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THE EXPERIENCE OF CHRONIC SORROW IN PARENTS WHO HAVE A CHILD DIAGNOSED WITH A SIGNIFICANT DISABILITY: INVESTIGATING CHRONIC SORROW ACROSS PARENTAL LIFE

A DISSERTATION

SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS

FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

IN THE GRADUATE SCHOOL OF THE

TEXAS WOMAN'S UNIVERSITY

DEPARTMENT OF FAMILY SCIENCES

COLLEGE OF PROFESSIONAL EDUCATION

BY

AMY SUE PATRICK-OTT, B.B.A., M.S.

DENTON, TEXAS

DECEMBER 2011

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To the Dean of the Graduate School:

I am submitting herewith a dissertation written by Amy Sue Patrick-Ott entitled "The Experience of Chronic Sorrow in Parents Who Have a Child Diagnosed With a Significant Disability: Investigating Chronic Sorrow Across Parental Life." I have examined this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy with a major in Family Therapy.

Dissertation/Theses signature page is here.

To protect individuals we have covered their signatures.

DEDICATION

To my sons, Joshua Tyler Patrick and Jesse Lawrence Patrick, I thank God for the privilege of being your mom and to see you grow into strong and grounded young men. I am thankful that I was able to enjoy those endless hours of work on my dissertation with the sounds of Joshua's stereo playing "This is Your Life" by the Newsboys and Jesse's intermittent explosions from his video games filling the air as I typed.

To my husband, Brian Leroy Ott, thank you for your love, support, patience and sense of humor. The answer to your question, "Are you done writing in that stupid ole book?" Yes I am finally finished!

To my parents, Grant and Elaine Higgins, your strong examples and encouragements while I was growing up have helped me become the person that I am today. That familiar phrase of "You can be anybody you want to be!" has been a sweet reminder that I have followed your advice all through my life.

To my personal savior, Jesus Christ, you have led me on a wonderful and difficult journey to this place. It is a gift that you placed in me long before I knew what it meant to follow your calling and to be blessed with the desires of your heart.

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ABSTRACT

AMY SUE PATRICK-OTT

THE EXPERIENCE OF CHRONIC SORROW IN PARENTS WHO HAVE ACHILD DIAGONOSED WITH A SIGNIFICANT DISABILITY: INVESTIGATING CHRONIC SORROW ACROSS PARENTAL LIFE

DECEMBER 2011

The focus and purpose of the this qualitative study is to describe parental experiences across the life cycle following the diagnosis of significant disability in their child and the concept of Chronic Sorrow described by Olshansky (1962). The study also hoped to provide avenues of expanding the Family Life Cycle theory (Carter and McGoldrick, 1988), The Contextual Approach to Family Stress Theory (Boss, 2002) and Ambiguous Loss (Boss, 1999, 2006) to become more inclusive for families who have a child with significant disabilities. Discussion surrounding Family Systems Illness Model (Rolland,1994) and Experiential Family Therapy (Whitaker, 1989) were also included to provide understanding regarding the adaptations made by families and the use of Experiential Family Therapy with this particular family system to promote continued growth across the life cycle. Purposeful and Snowball sampling methods were used to contact 10 families living in the North Texas. Participants were asked to engage in audiotaped face to face interviews with the primary researcher. Responses to the research question and central prompts were transcribed from the audiotaped interviews and entered into a Word document for the purpose of coding. The coded data was studied

and nine primary themes were identified. These primary themes were: (1) reaction to the diagnosis, (2) barriers (medical and informational), (3) adjustment (spousal, family, siblings, extended family), (4) resiliency, (5) supports (extended family and community), (6) hope, (7) future, (8) chronic sorrow, (9) individual adjustment. These primary themes were then compared to those developed by Boss (1999, 2006) in her depiction of Ambiguous Loss. Adaptations to these themes were decided and were condensed into seven final themes: (1) The Initial Reaction of Chronic Sorrow to the Diagnosis, (2) Finding Meaning in an Overwhelming Situation, (3) Tempering Mastering of Parenting a Child with a Disability, (4) Normalizing the Ambivalence of Parenting, (5)Parents Restructure their Identity, (6) Discovering Hope in the Redefined Family, and (7) Ambivalence about the Future.

This study discovered through the interviews with the parent participants that the experience of Chronic Sorrow began soon after receiving the diagnosis of significant disability for their child even though they did not have a term to describe the sense of loss being experienced. Parents in this study experienced multiple changes in their ideas regarding the diagnosis of disability, understanding the role of parenting and lifelong caregiver, involvement and connection of extended family and the decisions surrounding the future for the parent as an individual and for the child as they aged. Chronic Sorrow was found to be an experience that lasts across the life cycle, it is not a time bound concept, nor does it resemble a grieving process which has been associated with the loss of a loved one. Chronic Sorrow shares some similar components with Ambiguous Loss, and could be considered a Chronic Stressor as described in the Contextual Model of

Family Stress Theory (Boss, 2006). The study also provided possible inclusive adaptations to the Family Life Cycle Theory (Carter and McGoldrick,1988) to include the disability diagnoses into the theory of the life cycle as well as adding an addition component to the theory that includes the process of the launching the child back into the home after school servicers have ended.

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CHAPTER I

FAMILIES OF CHILDREN WITH SIGNIFICANT DISABILITIES

Introduction

Parents with children often have preconceived ideas, dreams, hopes, and even aspirations beginning even before the child is welcomed into the family. It is a part of what is termed human development. Most parents attend birthing classes, parenting classes and read books about becoming new parents with the expectation that this new found knowledge will be put to use immediately upon the arrival of the child. What happens to these ideas, thoughts, dreams, hopes, and aspirations when the child that is welcomed into the family is *not* what was expected? What happens when the developmental milestones do not unfold as once presumed? What happens when the parenting books read and shelved in an easily accessible place now become reminders of lost dreams replaced with the haunting realization that the child that is now a part of the family does not fit into the developmental criteria presented by parenting experts? The present reality for parents when their child has significant disabilities involves numerous questions and, at first, few answers. The disparity between available information, any remaining parental expectations, and the increased need for daily care for a child that is significantly disabled brings an increase in the emotions and reactions that are experienced by parents of children with disabilities over the lifespan.

Chronic Sorrow is a term that has generated many images and definitions for professionals working as mental health workers, nurses, and service providers with

families who have children with special needs. Coined in a 1962 seminal article written by Simon Olshansky, the study director of the Children's Development Clinic (Cambridge, MA), this term has sparked 40 years of research into the experience defined as Chronic Sorrow. Olshansky (1962) believed that Chronic Sorrow is a phenomenon that occurs throughout the lifespan of the parents and he emphasized the idea that parents should be accepted, by professionals, as individuals experiencing a normal reaction to a tragic event that has happened and is continuing to unfold across the life of the child, the parents, and the family. The tragic event is described as the parents' realization that their child has a significant disability and, as they grow physically, emotionally, behaviorally and cognitively, the dependence of these children will remain unchanged.

When the parents realize that the level of dependence of their children will remain at a high level for the rest of their lives, parents are often overwhelmed by the changelessness of their situation. The changelessness of the parenting role combined with their duties of caregiver, protector and decision maker that will continue through the years is made more poignant by the realization that the unending dependence of the child would end only by the death of the parent which becomes the basis for Olshansky's concept of Chronic Sorrow. Olshansky explained Chronic Sorrow as the *ebb and flow* of the sorrow which surfaces and resurfaces throughout the parent's life long experience because of the continual need for parents to complete multiple care giving duties for the child that extend and continue into the adult years such as continued spoon feeding, toileting for incontinence, and constant supervision to be sure that the child is safe. Although Olshansky viewed each family's experience as a unique response to the

disabling condition of the child, the similarities of sadness and sorrow identified in and by parents seemed linked to the realization that any typical development of the child would not be achieved nor would parents experience the independence or launching that is expected by the majority of parents as their child moves into adulthood. At the time of his 1962 article, Olshansky's concept of Chronic Sorrow was in sharp contrast with the more prevalent theory of the day which was psychoanalysis.

Solnit and Stark (1961) used psychodynamic theory to suggest that the term *mourning* was the most concise way to describe the sorrow experienced by parents of children with significant disabilities. Solnit and Stark theorized that the object of loss as experienced by the parents of a child with mental retardation was consistent with a traumatic event which could then lead to fear and anger toward the child. These researchers suggested that parents of children with multiple disabilities who struggled with emotional adjustment, marital conflict, sadness, anger and isolation across many years had become neurotically fixed in their grief. In their writings, they described parental fixation on loss as "the ghost of the desired expected healthy child continu[ing] to interfere with the family's adaptation to the defective child when the mourning process becomes fixed as the sustained atmosphere of the family" (p. 532). The parental experience immediately after the diagnosis was seen as a critical event because it was the parental post-diagnostic reaction that was thought to be a pivotal step in their acceptance or rejection of the child. Solnit and Stark assumed that having a child with a significant disability could freeze the emotional processes of parents in a state of grief for the child that "was not" and could, therefore, create an atmosphere of sadness which would

prevent cohesiveness in the family. This psychoanalytic orientation provided a linear model of cause and effect that was challenged by the work of Olshansky.

Working as director of a children's rehabilitation clinic, Olshansky (1962) supported the notion that most parents did accept their child's medical diagnosis based on his experience that parents were typically the first people to notice delays in their children's developmental progress which led to their seeking assistance from medical or rehabilitation professionals. Olshansky viewed parental acceptance as the ability of parents to first adapt to their experience of sorrow that followed their child's diagnosis and then learn to mobilize their efforts to parent and get to know the child they had. Olshansky also observed that parents experienced an *ebb and flow* to their sorrow and considered this a part of the natural process of learning about their child and their subsequent realization that their child might never develop past a particular point in the well-researched cycle of development. Olshansky named the ebb and flow of sorrow across the lifespan of the parent – Chronic Sorrow. Olshansky's work moved the experience of having a child with significant disabilities from the psychoanalytic medical model into a wellness model advocating the need for professionals to become more in tune with the changes occurring within the parents as individuals, the spousal system, and the family as parents began to know and understand the child they had been given rather than the child that was dreamed of or anticipated. Researchers in the field of nursing report that the concept of Chronic Sorrow as outlined by Olshansky's work explains the grief of parents of living children better than Kübler-Ross's stage model of grief.

More recently, researchers in the field of nursing (Burke, 1989; Damrosch & Perry, 1989) have turned to Olshansky's concept of Chronic Sorrow to provide a better explanation of parental grief than they found in the five stage model of grief suggested by Kübler-Ross (1969) which consists of anger, denial, blame, bargaining, and acceptance. While this stage model has been very useful for describing the experience of death and dying, it has been less useful in describing the chronic experience of sorrow for parents adapting to lifelong changes. Researchers from the nursing field (Fraley, 1986; Phillips, 1991) have worked to expand the concept of Chronic Sorrow into a theoretical model that describes the experience of parents and family living with a family member diagnosed with a chronic illness. Other researchers (Seideman & Kleine, 1995; Wikler, Waslow, & Hatfield, 1981) presented concepts thought to fit the description of Chronic Sorrow with hopes that it would facilitate understanding for individuals who were chronically ill, the bereaved family members, and the caregivers. Eakes, Burke, and Hainesworth (1998) who researched Chronic Sorrow as a reaction to loss due to a life of extended illness explained the phenomenon as a 'the periodic recurrence of permanent pervasive sadness or other grief related feelings associated with a significant loss" (p. 179).

Only one major book and research article have been published within the last ten years from the social work field and family science field that examined the experience of chronic sorrow in families (Roos, 2002) and parenting a child with significant disabilities (Patrick-Ott & Ladd, 2010). Roos presented the concept of chronic sorrow from the viewpoint of the Gestalt therapeutic model and the ultimate struggle parents experience as they try to understand how the presence of a child with disabilities changes the adult's

view of their life and their realization that their very dependent child would be left behind at the time of the parent's death. Patrick-Ott and Ladd discussed the differences and similarities between the construct of Ambiguous Loss from the Contextual Approach to Family Stress (Boss, 2002) and Olshansky's concept of Chronic Sorrow. Patrick-Ott and Ladd described the experience of chronic sorrow by presenting a case study description of one parent with a child who has significant disabilities. The case study provided some evidence concerning the ebb and flow of Chronic Sorrow in combination with the ambiguity of loss when considering parental expectations for the child's across his/her life as well as for the life of the parent.

Statement of the Problem

The ability of parents to reorganize and reframe the loss of their hopes and expectations for their own lives as adult and the life of the child with significant disabilities across the lifespan has been explored in a limited way. The concept of Chronic Sorrow has rarely been analyzed from the wider family perspective in regards to the effect on siblings in the family, effect on the ability to maintain employment by parents, or the effects on the marital relationship. Researchers have not explored the existence of Chronic Sorrow in conjunction with reframing, reorganization, and the meaning attributed to the experience of raising a child with significant disabilities by parents across the lifespan. This gap in research has led to the misunderstanding of the parental response to having a child with significant disabilities as one that often includes denial of the presence of the disability and failure to accept the reality of the lifelong

disabling condition of their child rather than due to the ebb and flow of Chronic Sorrow found in the behaviors and statements exhibited by this group.

Purpose of the Study

This research study explored the experience of families who have a child with significant disabilities through an in-depth case study approach investigating how parents experience the ebb and flow of Chronic Sorrow both currently and retrospectively as it is linked to the ultimate changelessness of the parental role and the continued dependence of the child. It has been theorized that when this type of family system experiences events that are symptomatic, stressful or dysfunctional, the momentum of change is slowed (Burke, 1989) and even stopped or fixed (Solnit & Stark, 1961). This researcher also investigated these ideas of slowed momentum and fixation through case studies designed to use the self-report of parents to identify their experience of raising children with significant disabilities.

The purpose of this research study was to challenge the notion that this family system is fixed in their inability to deal with their child's significant disabilities and move forward through their family life cycle stages as suggested by Burke (1989) and Solnit and Stark (1961). Second, this researcher challenged the notion that families are not able to adapt to their child's medical diagnosis or ultimately accept the reality that they are the parents of a child with a disability.

This researcher supports Olshansky's (1962) notion that the acceptance of the disability is not the primary factor that parents face; instead, it is theorized that parents are challenged over their lifespan with multiple and continual situations concerning their

child's significant disability and that they must learn to manage the presence of chronic sorrow in order to gather resources to mobilize their energies in order to move forward. The acceptance of the reality that they are the parents of a child with significant disabilities is a process the parent completes repeatedly over the course of their family life cycle. This researcher explored the idea that the transitions experienced by families with children who have significant disabilities would be in fact, linked to the acceptance that their preconceived reality about parenting must be reframed in order for their successful transition and movement through the life cycle.

Theoretical Frameworks

The Family Life Cycle Theory (Carter & McGoldrick, 1988) focuses primarily on family development over time. Families with children who have significant disabilities do not follow the same transitional life cycle stages that typical families traverse using the chronological and developmental trajectory of their child as the basis for understanding typical development. Rather, families with a child identified as having multiple and significant disabilities follow a different and less understood developmental cycle that is unique to the child's disability; in this situation, the stages based on "typical" development and the chronological age of the child do not apply. The categorical stages depicted in the Family Life Cycle theory explaining the chronological age of the child do not present a good fit when studying this family system.

Boss (2002) expanded Family Stress theory to include contextual aspects such as cultural meaning, development of the family, and the constitutional make-up of those individuals which comprise the family. With this expansion, Boss hoped to move the

theory passed the linear ideas of the cause and effect of stress to one which considers the perceptual shift regarding the meaning of stress, how families may respond to both an internal and external stressor by adding the variables of ambiguous loss and the outcome related to the perception of the situation causing the stress, boundary ambiguity. In the expanding of the Family Stress Theory, Boss (2002) also added the consideration of chronic stressors. The added consideration of chronic stressors presents an opportunity for the addition of the concept of Chronic Sorrow to be defined as a chronic stressor for families who have children with significant disabilities. Since chronic stressors are defined by Boss (2002) as those that persist over long periods of time when the evidence of the stressor may not be truly understood to outsiders or even to extended family (p. 55), the experience of chronic sorrow could be a reasonable addition to this theory.

The Family Systems Illness Model (Rolland, 1994) provides distinctive descriptions of the family system when it is faced with chronic illness or disability. The descriptions of centrifugal (outside the family focus) and centripetal (inside the family focus) can provide yet another avenue of understanding families who have children with significant disabilities, in particular, the required transitional movement between centripetal and centrifugal as they are linked to the needs of the child with significant disabilities.

The Experiential Family Therapy Model (Whitaker, 1989) presents a humanistic approach to family development and the emotional experiences that follow this maturation process. Therapeutic interventions found in the Experiential Family Therapy framework are molded to consider the emotional tensions experienced by parents who

have children with significant disabilities. Whitaker (1989) proposed that the struggle between the process of the development of personhood and the distinct emotional process connected to this developmental experience provides the elements to individual growth. This therapeutic model accepts the emotional processes found in the lives of parents who have a child with a significant disability as unique and distinct experiences that are difficult but not abnormal or pathological in nature. When considering the concept of Chronic Sorrow, this researcher suggests that this model of therapy does acknowledge and respect the uniqueness of the struggle for each family and recognize the subsequent growth which transpires in the lives of each member of this family system.

Research Question

What is the long term experience of parents who have a child diagnosed with a significant disability using the concept of Chronic Sorrow as the primary focus of this case study research?

Central Prompts: The following prompts were used to guide rather than direct the interviews:

1. Parental reaction to the medical diagnoses of their child.
2. Parental experience of the loss or delay of their child's developmental milestones.
3. Parental experience of raising children who have a significant disability alongside children without special needs.
4. Parental experience of marriage or being single while raising a child with a significant disability.
5. Parental experience of support from extended family.

6. Parental sense of loss of self over time.
7. Parental reaction to the changelessness of their role as parental caregiver.
8. Parent's ability to discuss their child's future after the parent's death.

Definition of Terms

The following definitions are given to help the reader understand the terminology used throughout the research study.

Centripetal Periods: Rolland's (1994) description of the family's processes used to organize their lives around the child in order to preserve some element of routine and predictability. This can also be characterized by seeing the family system occupying an inside-the-family focus (p. 474).

Centrifugal Periods: Rolland's (1994) description of the family's processes used in raising adolescent children, preparation for launching into adult life and can be characterized by loosened family boundaries, encouragement of individual member growth and development and outside interests (p. 494).

Changelessness: As the child grows physically, emotionally, behaviorally and cognitively, they remain unchanged in the development of independence. This interaction between the parent and child would continue through the years as one requiring consistent intervention and monitoring by the parent; thus the changelessness of the parenting role becomes the basis of their experience of chronic sorrow.

Chronic Sorrow: Chronic Sorrow is a prevailing sense of loss that ebbs and flows throughout the lifespan of parents of children with disabilities. As an ongoing experience, chronic sorrow surfaces at different times in the life of family members as a

result of various experiences or the lack of expected experiences across the lifespan. The characteristics of chronic sorrow are similar in families, yet unique, to each person's experience and situation (Olshansky, 1962).

Ebb and Flow: This phrase describes the experience of Chronic Sorrow as it waxes and wanes over the lifespan of the parent with a child with significant disabilities especially as it is associated with parental care giving duties that extend past the infancy stage into the adult years (continued spoon feeding, incontinence, continued supervision, and poorly developed self-help skills).

Milestones: The Transactional Model of Development (Davies, 2004) views milestones as those times when the child begins to expand his environment through interactional exchanges with parents and with objects as the child's growth and development physically, behaviorally, cognitively and emotionally also expands. Developmental transitions are taken from the Family Life Cycle Theory (Carter & McGoldrick, 1988) to provide a concise conceptualization of the developmental transitions experienced by families as they move through the life cycle.

Significant Disability: Significant disabilities are also known as multiple disabilities and severe multiple disabilities. *The Individuals with Disabilities Education Act* describes significant disabilities as those that include "concomitant impairments (such as mental retardation, blindness, mental retardation and orthopedic impairment, etc). The combination of impairments causes severe problems so that the individual cannot be accommodated in special programs solely for one of the impairments" (34 C.F.R. §30[b] [6]).

Delimitations

1. Participants were limited to parents who have a child who has met the criteria of having multiple disabilities that significantly impair the child's verbalization, cognitive, physical skills as well as the impairment of independent living skills.
2. Parents who participated have their child residing in the home with them at the time of study participation.
3. Parents of children and adult children who have a diagnosis of learning disability, ADD, ADHD or documented mental illness were not included in this study.

The Self of the Researcher

This researcher is the mother of a 25 year old son who has multiple and significant disabilities. Parenting a child with significant disabilities and working within the field of disability service delivery and community mental health has provided the researcher with insights and knowledge about the experiences lived by parents who have children with significant disabilities. The researcher's family experience was considered to be an asset when interviewing parents for the study as the level of trust and understanding for the concept of Chronic Sorrow was understood from the viewpoint of a professional and a parent.

Summary

The ability of parents to reorganize and reframe the loss of their hopes and expectations for themselves as parents and for their child with significant disabilities has been explored in a limited way. This research study explored the experience of families who have a child with significant disabilities through an in-depth case study approach

investigating how the parents experience the ebb and flow of chronic sorrow both currently and retrospectively as it is linked to the ultimate changelessness of the parental role and the continued dependence of the child.

CHAPTER II

REVIEW OF LITERATURE

This literature review will examine previous research studies that support the focus of this study on the further development of the concept of Chronic Sorrow, especially contributions from the field of nursing that expand the theoretical framework that explains the experience of families with a child diagnosed with significant disabilities, as well as research related to the lived experience of parents. In 2000, Census figures indicated that disabilities affected 20% of all Americans, or that nearly one in five individuals were in need of personal assistance to carry out daily life activities. Nine million people of this 20% were in need of personal assistance to carry out daily life activities while 7.2 million of this nine million received care giving and personal assistance from family members and about 4.5 million lived with family. (Retrieved from U.S. Census: http://www.census.gov). These numbers present a staggering realization that disabilities affect many lives. The prevalence of those with disabilities residing in the family home has varied over time.

Ferguson (2002) provided a historical aspect to the study of children with mental retardation and their removal from the family home in the early 1900s. The practice of removing children diagnosed with mental retardation was initiated to "break the connection between poor parents and children with disabilities and to allow the professionals to assume the parental role in asylums and reform schools" (p. 125).

professionals to assume the parental role in asylums and reform schools" (p. 125). Olshansky's theory of Chronic Sorrow emerged during what Ferguson called the "psychosocial approach [concerning] the suffering parent" (p.126). It was during this time that researchers looked at parents through the lens of grief and suffering and the parent's ability to accept the child with a disability into the family. Attention was focused on the interactions playing out in the family between parent and child and included such considerations as a concentrated investigation of the contextual approach of the family system and the reality constructed within it. A series of studies completed by Farber (1959, 1960a, 1960b, 1960c) provide insight into how families are affected by the long-term experience of raising a child with mental retardation.

Farber (1959) conducted a large qualitative study of 102 families that led to her examining family integration in 79 families when their child diagnosed with mental retardation continued to live at home. The researcher was exploring the notion that both parents and the siblings who appeared to be developing "typically" within the family might also experience an "arrest in the family cycle" (p. 49). The independent variables of marital integration, sex of the target child (45 males, 34 females), social status, and degree of dependence on the mother and the sex of the typical siblings were found to be related to the dependent variables of parental marital integration and sibling role tension. The researcher discovered that the marital relationships were more adversely affected in families who had boys rather than girls diagnosed with mental retardation. This adverse marital effect was also more pronounced in families whose social status group was considered to be in the low rather than high or middle class range.

In that same study (Farber, 1959), the age of the child with mental retardation did not have an effect on the degree of dependence on the mother but did have an adverse effect on the adjustment of typically developing brothers and sister in their family roles. This study underscores the belief that having a child with mental retardation could present considerable difficulties for the different components of the family system. Farber (1960a) reported on additional variables from her original sample of 79 parents: religious affiliation (not significant), birth order of the child with mental retardation, resiliency factors that protected against the arrest in the family life-cycle, and marital integration measured before and after the birth of the child with mental retardation. Those parents who did not have expectations about their child's development and whose child appeared to meet fewer developmental milestones over time reported that their child became more dependent on the mother and negatively affected the forward motion of the family cycle. Farber (1960a) theorized that this arrest would inhibit family members from launching and the parents from moving into a post-launching stage of the family.

Families in Farber's study (1960b) reported experiencing both alienation and social isolation from the community and noted that traditional child raising strategies were not useful with their child diagnosed with mental retardation (Farber, 1960b). This lack of useful strategies led to the family reporting less internal connection and less independence among family members. The researcher discovered that couples who had defined family values and roles, and reported a strong marriage both before and after the birth of the child with mental retardation were more successful than those families who had difficulties with values, roles and marital strains. In essence, the research stated that

family support, community support and financial ability played a substantial role in raising a child with mental retardation.

Farber (1960c) asked 233 families to rank a list of 10 domestic values in order of their importance to a successful family. This researcher found three types of family organization: child-oriented (show high regard for traditional values like economic security, religious unity, healthy children), home-oriented, (emphasis on home and children and emotional security of the family), and parent-oriented (stress placed on companionate marriage). She found support for the home-oriented pattern in which parents who care for a child with mental retardation begin to lower their expectations for occupational success, focus their lives and work toward the home, and draw their primary emotional support from within the family system. Instead of identifying support for the two remaining patterns, Farber identified an integrated pattern among 83 families that included an equal division of labor for household responsibilities and non-role specific caring for the children. Farber hoped to identify strategies to help families integrate their child with mental retardation successfully into the family system.

Solnit and Stark (1961) followed up Farber's studies with an article depicting the daily life of families with a child who has mental retardation as one that was filled with grief, mourning and guilt. Their study looked at the family from the standpoint of the mother being overwhelmed with the birth of a "defective child" resulting in a trauma (p. 524). Their work was based on the Freudian theoretical view of a mother's reactions to the birth of a child with handicaps. The theory held by these researchers was one that conceptualizes the birth of a child with "significant deviations, such as gross retardations

or obvious congenital defects, may limit or interrupt the mother's developing capacity to accept the new child who is totally dependent upon her" (p. 525). Since the expected baby was not what was dreamed, the mother is torn between what she has and what she wished for. The developmental journey of motherhood is influenced by her past experiences with parents, siblings and other life events used to measure this experience.

While Olshansky (1962) believed that parents who have a child with mental retardation "suffer from a pervasive psychological reaction, chronic sorrow, that has not always been recognized by the professional personnel, physicians, psychologists and social workers who attempt to help them" (p. 192). He asserted that whether the child is at home or placed in an institution, chronic sorrow was still present. Olshansky felt the professional community was too quick to state that parents were consistently denying their child had mental retardation. Chronic Sorrow, according to Olshansky, encompassed feelings of guilt, shame and anger at some point, however, he did not view these feelings as being a neurotic manifestation, "but a natural response to a tragic fact" (p. 192). In his opinion, parents were being misunderstood by the very professionals who were working with them as the parents attempted to try to make sense of it all.

Olshansky (1962) found it confusing for professionals to ask parents to accept the mental retardation in the child, since this had already become a reality through their continual care and subsequent search for assistance in this task. The acceptance that professionals were asking parents to accomplish was in essence to move beyond the experience of the chronic sorrow that was now constant since the diagnosis. The realization that the parent was experiencing chronic sorrow was often overlooked and

mislabeled as denial. Olshansky did not believe the concept of Chronic Sorrow was time bound or a concept that could be fit within certain concepts that would then follow pre-established steps; he understood chronic sorrow to last a life time. As the child begins to grow and mature, but in many ways stays the same in the dependency and inability to become self sufficient, the realization that another parental expectation had been lost again, brings the experience of chronic sorrow back with the need for deeper acceptance. This sorrow is experienced throughout the lifespan, waxing and waning according the circumstances or situations that arise while parenting their child. Olshansky was blunt in his explanation regarding the ending of chronic sorrow. In his 1962 article, he stated that "concern about what will happen to his child after he is dead may be a realistic concern for a parent, or it may be associated with death wishes, either for himself or for his child. Release from his chronic sorrow may be obtainable only through death" (p. 193).

Olshansky (1962) challenged the existing view as proposed by professionals that parents accepted the diagnosis of their child once and for all time, as being too rigid. Olshansky's main concern was that professionals be aware of what they were asking parents to do when the professional asked parents to accept the diagnosis. He suggested that those professionals who wanted parents to accept their sorrow or sadness and "move on" were asking parents to do something that could not be achieved until the death of either the parent or the child with mental retardation. He believed that by developing an understanding that chronic sorrow is a valid experience for parents of a child with significant disabilities, the professional could help the parent better move toward understanding their experience and accepting the ebb and flow of chronic sorrow.

Olshansky's therapeutic position allowed the parent to increase their ability to manage their lives with their child and within their family.

Researchers in the field of nursing continued examining the belief that the birth of a child with disabilities created a context of grief and mourning in parents. Young (1977) outlined Chronic Sorrow as an eight step process with the inclusion of Olshansky's Chronic Sorrow as one of the stages used to described "parental stage of distress" (p. 41). This eight step process asserted that the parental stage of distress included one of two types of responses: maladaptive or adaptive, with the ultimate resolution to chronic sorrow being the death of the child or the death of the parents. Young's research conceptualizes the theory of chronic sorrow in the same context as the Grief Model proposed by Kübler-Ross (1969). This researcher's most notable addition to Olshansky's (1962) theory was the idea that parental adaptation to their child's disability would either be adaptive or maladaptive in nature.

Other researchers endeavored to relate the experience of a child with significant disabilities as one which created a sense of grief and loss. Bristor (1984) proposed a wholistic model for grieving (p. 25) that equated the birth of a child with significant disabilities with a crisis. According to this author, the attachment between parent and child was the major focus of this model; he concluded that the mother would not be able to accept her child with a significant disability. The wholistic model studies how the mother's grief and sense of loss affects her attitudes and values across these dimensions: biological, emotional, behavioral, and spiritual (p. 27.) This wholistic model is comprised of six stages including the notion of grief as outlined by Kübler-Ross (1969).

The final stage of the wholistic model occurs when the parents "transcends the loss" (p. 29) and moves beyond the point of looking for reason why something cannot be accomplished because of the disabilities in the child, but to a time when they can derive enjoyment for their child regardless of the handicap and realize potential for the future. It is again noted that the idea of chronic sorrow being a time bound concept is still prevalent in early research.

A change in the conceptualization of chronic sorrow in the field of nursing began to surface in the early eighties and nineties (Wilker, Waslow, & Hatfield, 1981; Fraley, 1986; Damrosch & Perry, 1989; Burke 1989; Phillips, 1991; Seideman & Kleien, 1995). Professionals were beginning to notice that parents were still experiencing chronic sorrow long after the diagnosis of their child. This understanding that the idea of a time bound theory of chronic sorrow by early researcher data precipitated more research into the experiences of families who had children with significant disabilities.

A qualitative study was conducted by Wikler, Waslow, and Hatfield (1981) in an effort to understand level of differences in adjustments made by parents of children with special needs. Their study asked one hundred social workers and one hundred parents about the experience of living with a child who has special needs and the adjustments made to accomplish this task. The researcher identified a small number of professionals who voiced their belief that chronic sorrow was not a time bound occurrence, it was however one that continued across the lifespan. Wikler et al. (1981) suggested that chronic sorrow was a normal response by a parent after receiving a diagnosis of special needs for their child and that both "a continuum of services across the lifespan should be

provided as well as information regarding helpful management of periods when chronic sorrow is indeed more prevalent was needed" (p. 70).

Burke (1989) performed research with 47 mothers of children with myelomeningocele and the results from her study revealed parental moods of grief, anger, guilt and sorrow. Burke also noted that chronic sorrow was more prevalent among parents when developmental milestones were not attained by their children or if their child's medical condition worsened and care giving demands increased. A majority of mothers (91%) involved in this study reported chronic sorrow as measured by the initial draft of the future Burke Chronic Sorrow Questionnaire (1989).

Burke, Hainesworth, Eakes, and Lindgren (1992), also known as the Nursing Consortium for Research on Chronic Sorrow developed the Burke Chronic Sorrow Questionnaire to help facilitate an understanding of when chronic sorrow occurs and what sort of characteristics are displayed during these times across the lifespan. The developers still held true to the concept that chronic sorrow was a form of unresolved grief, but that it was not pathological. Their description of chronic sorrow states

> The person experiencing chronic sorrow is typically highly focused and functional in the presence of the ongoing loss. The disability or chronic condition may require performing new tasks, making far-reaching decisions and modifying lifestyles. Chronic sorrow does not impede the ability to meet these challenges (p. 233).

The authors noted that no study regarding chronic sorrow across the life span had been completed to that date; research during this time was directed at the issues and concepts related to parental reactions to their child's disability. The results of their study recommended that professionals needed to be aware of "specific ongoing support

measures" (p. 242) at the time when developmental milestones are expected by parents but not achieved by the children.

Hobdell and Deatrick (1996) performed a content analysis on the Burke Chronic Sorrow Questionnaire with a group of 68 mothers and 64 fathers of children with neural tube defects. The findings of this study confirmed the results performed by earlier researchers Burke (1989) and Wikler et al. (1981) regarding what they termed as triggers in mothers and fathers in their response to the child's disability. Chronic sorrow was again confirmed to be a phenomenon much different then grief and loss, it is not time bound, and it does not have a linear or time-bound resolution. Their content analysis was followed up with another qualitative study by Mallow (1999) which looked specifically at the experience of 300 families living in South Dakota who had children that were developmentally delayed. This study sampled only married couples who were members of a local support organization and had a child with mild disabilities living in the home. The final sample consisted of 19 parents, with varying diagnoses including ADHD and Tourette's syndrome. Mothers and fathers differed in how they adapted to the experience of having a child with a disability; mothers were found to report feeling chronic sorrow more than fathers did. Chronic sorrow was noted by these participants when events or situations caused the "feeling of sadness all over again" (p. 34). It was interesting to note that the concern that triggered the chronic sorrow as reported by the mother was the management of health care crisis while fathers reported that it was the comparison of whether the child did or did not meet expected social norms.

Researchers Kearney and Griffin (2001) in the field of disability research conducted a phenomenological study with parents of children with developmental disabilities over an 18 month period. Their study used both face to face and telephone contact to examine the disruptions the parents experienced in their family. Two major themes that were identified through this research were parental joy and sorrow. The researchers noted that the "joy is defined by sorrow which has come before…the parents' experience is one of paradox and ambiguity and is full of conflict and confusion" (p. 586). This study brings to the forefront the notion that living with a child who has multiple disabilities is a unique and contextual situation. The authors noted that parental meanings and the realities they ascribed to their feelings and emotions were often in flux between sorrow and joy across their life cycle.

Todd and Jones (2005) engaged in a qualitative research study with mothers (mean = 48 years) of adolescents diagnosed with significant mental retardation living in the United Kingdom. The mothers reported that they felt that their lives had initially been ordinary with their children until the middle years of adolescence. It was at this point mothers indicated that their sense of self had been lost in the caring of their child. The person each woman thought they would have been at middle age was still on hold as the changelessness of the child in certain areas of development became more noticeable. The sense that the world continues on with normalcy while these parents still grapple with the non-normalcy of caring for a child with significant disabilities throughout the life cycle is evident. Although the study did not identify the chronic sorrow theme, the responses found in this study match many of those conducted by other researchers.

The coping styles of parents with children who have significant disabilities has been a topic of study for years as researchers have attempted to identify the varied coping skills of parents living with a child. Hobdell et al. (2007) conducted a study asking 67 families who have children were diagnosed with epilepsy to complete the Adapted Burke Chronic Sorrow Questionnaire (1989) and the Coping Health Inventory for Parents (1983). This study found that parents experienced chronic sorrow at high levels after learning of their child's initial diagnosis and their levels of chronic sorrow remained constant as time passed. Using CHIPS, these researchers identified that during the times of heightened feelings, parental coping styles related to chronic sorrow were "seeking and obtaining social support from others, making attempts to deal with psychological tensions and strain and attempts to maintain self esteem" (p. 81). The authors concluded that chronic sorrow was a valid experience.

Marshak, Seligman, and Prezant (1999) in "*Disability and the Family Life Cycle,*" discussed the psychological issues and every day difficulties experienced by parents who have children with disabilities. Using a developmental perspective, the authors cite some of the problems experienced in this family system stem from "the clash of developmental needs and access to the necessary opportunities and resources" (p. ix). Marshak et al. assert that individuals with disabilities are seen in the context of a child long after the childhood developmental stage has passed with the resulting need of professionals to consider this family system from a developmental lens due to the "disparities between traditional expectations and timing or the absence of developmental milestones" (p. x).

Marshak, Seligman, and Prezant (1999) discuss the specific needs of families who are parenting children with significant disabilities across the life span. The authors believe the process involved in the parent's first reaction to hearing about their child's disability as a time when they must "not only respond to the event itself, but also must confront their own belief about people who have disabilities" (p. 5). These authors also noted that parents must also grapple with those meanings and attitudes that other family members may have toward individuals with disabilities as their child remains a constant dependent on the parents across the lifespan for support and care.

The field of Family Sciences has approached the research of families who have children with multiple disabilities in a broad fashion. Rolland (1984, 1987, 1990, 1994, 1998, 1999, & 2002) promotes the Family Systems Illness Model that approaches the family from a normative stance using assessments and interventions formulated to help families who are facing chronic illness or life threatening conditions. According to this model, three distinctions are made when viewing a family that is experiencing an illness: (1) type of disorder, (2) time since the disorder was diagnosed, and (3) the variables that are present in the family system. Rolland distinguished this model by theorizing that the history of the family in their experience with illness and the onset of the disorder or illness all play important roles in the ways families function and ascribe meaning to living with chronic illness.

Rolland's integrated approach looks at the family through a normative and preventive lens to assess and provide interventions to families experiencing chronic and life threatening conditions (p. 460). Rolland discusses families who are living with

chronic and life threatening conditions as either centrifugal or centripetal, conceptualizations borrowed from the Beavers and Hampson model (1990). By combining the centrifugal and centripetal descriptions, Rolland explains that families adjust their life style according to the developmental tasks and energies within the system are directed to either the inward or outward tasks required to move through the life cycle transitions.

Walsh (2006) suggests that Family Resilience Theory can be applied to the study of chronic illness and care giving through an "integrated biopsychosocial approach to both psychiatric and medical disorders" (p. 219). Walsh describes resiliency as the family's ability to "bounce forward, rebounding and reorganizing adaptively to fit new challenges or changed conditions" in their lives (p. 85). The Family Resilience Theory focuses on the challenges presented in the family and then works toward strengthening those processes to lower the risks of dysfunction and facilitates healing and the promotion of strong family functioning. One way this is accomplished is through the provision of information, assistance with managing the demands of providing care to the family member as well as helping families develop realistic expectations for the family and family members involved. Another essential element of the Family Resilience Theory is consideration for "the many actual and perceived losses that can accompany a chronic condition, the loss of valued roles, functions in the family, loss of personal and shared hopes and dreams for the future" (p. 247). Family Resilience values the collaborative effort of families as they learn to construct new or renewed competencies, mutual support and the ability to prevail under duress (p. 25).

The Family Life Cycle Theory (Carter & McGoldrick, 1988) focuses primarily on family development over time. It has been theorized that when a family experiences symptoms, stressors or dysfunctions, the momentum of change is slowed (Burke, 1989) and even stopped or fixed (Solnit & Stark, 1961). Carter and McGoldrick (1988) propose that the theory of the Family Life Cycle is comprised of four stages: (1) the family with young children, (2) the family with adolescents, (3) launching children and moving on, and (4) the family in later life (p. 17). These authors theorize that the emotional processes experienced by family members in their transitions between life cycle stages and the second order changes made to proceed developmentally into the next stage are affected by stressors that can affect the family's momentum of change in either a negative or positive way. Family Life Cycle Theory looks at three primary aspects of family development: predictable changes, transitional patterns in the life cycle, and the role of therapy in assisting families through difficulties with these transitions (p. 4). Predictable changes as defined by the Family Life Cycle theory are those identified through the grouping of family stages:

1. Families with young children are focused on the acceptance of new family members into the system and learning to be parents,
2. Families with adolescents are moving toward independence and the adolescent and his/her parents are involved in increasing the adolescent's independence and autonomy,

3. Families who are launching their children are focused on moving the child into the independence of a young adult and moving the parent toward an end of parenting on a daily or continuing basis, and
4. Families in the later life stage without children are focused on the pursuit of individualized interests, subsequent losses associated with the death of a spouse, health and the aging issues (Carter et al.,1988, p. 17).

Boss (2002) views family stress in Contextual Model of Family Stress from several perspectives including: their unique cultural meaning of that stress, the development of that individual family, and the unique characteristics of all members within the family. Boss expanded Family Stress Theory past its linear notions of the causes of stress and effects on the family into a broader, focused investigation of the resilient strengths families used to meet the needs of the stressor. In this model of family stress, Boss expanded the theory to include a perceptual shift in the meanings of stress and how families responded to their internal and external stressors by adding ambiguous loss and the outcome related to the perception of the situation, boundary ambiguity. Boss defined different stressors in her expansion of the Family Stress theory; a stressor is defined as a chronic situation which persists over long periods of time when the evidence of the stressor may not be truly understood to outsiders or even to extended family (2002. p. 55). Boss describes ambiguous loss as a structural problem which leads to boundary ambiguity; the ambiguity of the stressor lies in the inability of the individual to obtain the needed facts about an event or situation that can facilitate a closure or ending. If the

family member experiences the facts necessary for closure then the family is unable to fulfill family roles and rituals – leading to the experience of ambiguous loss.

Boss (1999) described ambiguous loss as "an incomplete and uncertain loss" (p. 3) that occurs in two different ways: the family member can be physically present but psychologically absent, or physically absent and psychologically present. In a case study of one mother that struggled with ambiguous loss associated with the diagnosis of her son, Patrick-Ott and Ladd (2010) found that the parent grieved her inability to control or experience ordinary events with her child as well as experienced ongoing sorrow at the continuing losses over time for both the child and the family. Boss (2006) claimed that ambiguous loss is the "most stressful kind of loss because it defies resolutions and creates long-term confusion about who is in or out of a particular couple or family" (p. xvii). It is this level of stress created by the ambiguous loss that can affect the "path a family follows as it adapts and prospers…both in the present and over time" (Hawley & DeHaan, 1996, p. 293).

Neill and Kniskern (1982) discussed Whitaker's formulation of a healthy family as being "flexible in the assignment of the necessary roles to its members" (p. 18). Whitaker describes family development as one that moves along biologically determined time spans. As the family moves through stages of development there is "always a dynamic tension between the needs of individual members for individuation and the needs of the family system" (p. 18). In families that have children with significant disabilities, the role of the first born child may not be fulfilled because of the severity of the disability; therefore, the siblings who may be brought into the family later may be

asked, expected or elevated to this position as some point. In the Experiential Model, Whitaker (1989) holds the basic premise that family members have the right to be themselves, authentic, and that the family is robust, resilient, and holds unlimited potential. Whitaker & Bumberry (1988) described families as fertile fields for the development of intimacy, awareness and understanding. Whitaker (1989) explained the "challenges we all struggle with endlessly is that most of us live a fragmented life; we are either preoccupied with the horrors or the glories of the past, or we are preoccupied with the horrors and glories of the future" (p. 52). Whitaker proposed that we are human beings not human doings and it is when we learn to live in the present that we truly begin to live and grow from the experience of that moment. Whitaker understood the art of living as one that included the development of personhood, to become all that you can be by allowing the emotional context of the experience to flow.

Deficiencies

There is no evidence of any studies in the field of family sciences that have examined a sample of parents or families with a child having significant and severe disabilities. No research exists that has focused on the experience of parents across the lifespan of their child or of their experience with a child living at home who is a young adult with significant disabilities. However, it is apparent that other researchers have continued to focus on grief and loss as a linear experience rather than how it is included in a description of the experience of chronic sorrow (Young, 1977; Bristor, 1984). Consequently, this lack of research poses a problem for professionals and parents as both are experiencing a different reality – professionals are very ready to ascribe the parent's

experience of sadness to a time bound model of coping with the disability and to classify parents as being in denial of their child's disability and inability to accept their condition (Faber, 1959, 1960a, 1960b, 1960c; Solnit and Stark, 1961). Therefore, this researcher proposes to provide "empirical evidence about the relationship between the family system, parental coping, and the child's health to guide practitioners of all family and health related fields in the development of programs and provision of services for these families" (McCubbin & Huang, 1989, p. 436).

Summary

Chronic sorrow has a research base that is yielding data designed to validate it as a concept. Researchers have tested the concept of Chronic Sorrow in both qualitative studies and measured it through quantitative studies (Wilker, Waslow, & Hatfield, 1981; Burke, 1989; Hobdell & Deatrick, 1996; Kearney & Griffian, 2001). Olshansky (1962) proposed this concept at a time when professionals were looking at families that had a child with a significant disability through a pathological lens. He encouraged professionals to understand the ebb and flow of chronic sorrow in these families, to respect its existence by assisting families as they moved through the lifespan. This present qualitative study will strive to measure the concept of Chronic Sorrow through a case study method which will yield a rich, thick data set by which professionals will better understand how family members are affected over time by their child diagnosed with significant disabilities.

Conclusion

Chronic sorrow has been studied extensively over the past forty-six years. The concept of Chronic Sorrow has been validated through several studies involving many different populations; it most cases, researchers have not remained true to Olshansky's original concept that chronic sorrow is sorrow and that it is not time bound. As a concept, Chronic Sorrow is an ongoing experience that occurs over time and across situations in families of children with significant disabilities (Olshansky, 1962). For many professionals, chronic sorrow has been misunderstood which has resulted in many professionals tending to categorize the parent's experience with their child with significant disabilities as one marked by denial and a failure to accept the fact their child has a disability. Olshansky encouraged professionals to move past embracing a linear or simplistic definition of grief and move into understanding the ebb and flow of chronic sorrow in the lives of parents. According to this forward thinking professional, the end result would be a more open and flexible professional relationship that worked to assist with parents with learning to manage the demands that a child with disabilities can bring to a family system and providing a quality of care to the other members of their family.

CHAPTER III

METHODOLOGY

A qualitative case study as described by Stake, 2005 was select by this researcher to investigate the ebb and flow of chronic sorrow linked to the ultimate changelessness of the independence of the child with significant disabilities as reported by parents in eight family situations involving children ages 2 to 35. This case study approach looked specifically at how the role of the parent remains changeless as the development of the child is influenced by their disability and the reality that the full independence that typical children reach at about age 18 will not be achieved by a child who has significant disabilities.

The case study methodology used for this qualitative research was selected as an avenue to investigate these experiences, meanings, and descriptions given by parents of children with significant disabilities. Boote and Beile (2005, p. 3) defined good research as one "that advances our collective understanding." Peshkin (1993, p. 28) stated that the infinite path of qualitative research can "only be facilitated by a type of research that gets to the bottom of things, dwells on complexity and brings us very close to the phenomena we seek to illuminate." Marshall and Rossman (2006, p. 2) viewed qualitative research as "pragmatic, interpretive, and grounded in the lived experiences of people."

Creswell and Clark (2007) defined case study research as one that "involves the study of an issue explored through one or more cases within a setting or context" (p. 73).

Denzin and Lincoln (2005) described case studies as methods of inquiry, methodologies or research strategies. Creswell and Clark (2007) stated that the case study method of research is "one where the investigator explores cases over time, through detailed, in depth data collection which involve multiple sources of information" (p. 73). Through the case study model, this researcher investigated multiple aspects of the long-term experience parents have had dealing with such events as a missed milestone of their child playing on the soccer team or transitional stages such as their child leaving home for independent living. Marshall and Rossman (2006) understood this method of data gathering as a good source for primary information.

Sample Selection

This researcher gathered her sample so that parents of children falling into four specific age groups could be interviewed: two to six years, seven to ten years, eleven to seventeen, eighteen years and over. Both mothers and fathers were sought for this sample; it was required that participants speak English (Table 1).

Two sampling methods were chosen for this study: purposeful and snowball. This researcher gathered her sample through a web-directed purposeful sampling method which ultimately drew only one participant. This researcher chose a purposeful sampling method (Schwandt, 2007) to obtain a sample from the population of parents of children with disabilities seeking information regarding services, educational questions, and advocacy concerns from the Partners Resource Network. Creswell and Clark (2007) describe this method as one that "intentionally selects participants who have experience with the central phenomenon or the key concept being explored" (p. 112).

This purposeful sampling procedure was accomplished through a letter of agreement with Partners Resource Network (PRN). A website posting was placed on this PRN's main page and an also email posting to the organization's listserv.

One potential participant was found through the purposeful sampling method from the website posting made in agreement with Partners Resource Network Inc., the Parent Training and Information Center for the State of Texas, funded by the United States Department of Education. This interview was not included in the data analysis because the child's diagnosis did not fit the criteria outlined for this study. The diagnosis of that child's disability was mild traumatic brain injury and did not affect the child's ability to maintain some level of independence.

A second method, snowball sampling, proved to be more successful as eight additional families were recruited. The snowball sampling method is used when the potential participants are a part of a special population that may be difficult to locate (Babbie, 2004). In this case, the researcher contacted a parent she knew personally and asked that individual to assist in locating other potential participants for the study. The snowball sample consisted of eight families who have children with significant disabilities.

Initial contact regarding interest in participating in the research study was accomplished the participants emailing the researcher their interest to participate in the study and the provision of a telephone number to contact them. The researcher contacted each potential participant to discuss the study and to ask each participant to email the primary researcher personal contact information. The researcher followed up by emailing

the script, the consent to participate form, and the demographic questionnaire to each participant. Participants were asked to read the material, pose any questions they might have regarding the study back to the primary researcher through email or by phone call. Participants were instructed to sign the consent to participate and complete the demographic questionnaire and return that information to the primary researcher through mail or by email. Once the information was received, the researcher scheduled separate interviews at a venue identified by each participant. The data collection process of audio-taped, face to face interviews began in October 2010 and continued through January 2011.

Five interviews were conducted at the homes of the parent while the remaining two interviews took place in a private conference room at each participant's place of employment. While the interviews were expected to take two hours to complete, this researcher found that the participants responded positively to the central prompts and needed only between 50 minutes and one hour to share their story. Only two interviews took longer than the one hour length of time.

At the time of the face to face meeting, the primary researcher asked participants if there were any questions the participants might have regarding the course of the interview and confidentiality of their personal information and their identity and the identity of their child with significant disabilities. A list of agencies and counseling resources was given to all participants at the time of the interview meeting. All participants agreed to share their stories for this research study without incentives. All voiced the desire to share their stories with the hope that their experiences would help

other parents and professionals to understand and learn about what a life with a child with a significant disability brings to the life of the parent.

Marshall and Rossman (2006) explained that some sort of direct and immediate participation within the research environment usually becomes important in building and sustaining relationships with participants (p. 73). This study accomplished this important task by the researcher's sharing a brief introduction of her the life with an adult child who has significant disabilities prior to the face to face interviews. By sharing the thoughts, experiences, feelings and difficulties experienced by the researcher with the potential participants, creditability was established with the sample regarding the experience of living with a child who has significant disabilities.

Protection of Human Subjects

Protection of Human Subjects was accomplished by voluntary participation and informed consent was gathered. Participants were informed that they could stop their interview at any time. Recruitment of participants was conducted through the Partners Resource Network through the use of purposeful sampling and also by snowball sampling. The researcher posted information about the design and intent of the research study on the website of the Partners Resource Network. The information concerning the design and intent of the research study was also provided to participant located through the snowball sampling through email. Purpose of the research study, procedures and the potential risks were included in the online posting and in the email. Participants were given a list of referral sources if they experienced emotional discomfort during their interview. The sample did not exclude participants based on gender, marital status, race

or culture, education or income level. Parents who consented to participate were English speaking and had a high school diploma with the majority having a college education.

Data Collection

The researcher developed one over-arching research question and eight central prompts as a guide for the face to face interviews. The prompts were asked according to the direction the conversation took as parents discussed their experience parenting a child with significant disabilities across the lifespan. The researcher sought to capture the participants' thoughts, feelings and emotions in a storied fashion rather than a question and answer format. An atmosphere of "tell me your story" was the prevailing direction during the interviews with the central prompts being used as guides for the conversation between the researcher and the participants. It was originally estimated that the length of time for data collection would take ninety days. The first research participant was contacted in mid-October 2010 and interviews continued through January 2011. The researcher completed research data collection in approximately one hundred and twenty days. This time period allowed the researcher to complete a total of eight face to face audio taped interviews. Face to face interviews were limited to eight individuals as saturation of the sample was achieved.

Data from the research question and central prompts were collected via interviews that were audio taped, semi structured and open ended. The researcher informed each participant that he/she could ask to stop the interview at any time. All of the participants involved in the study continued with the interview until all prompts had been asked or the

participant had shared everything they wanted to share. Once the data was collected from the interviews, the researcher began data analysis.

Research Question

What is the long term experience of parents who have a child diagnosed with a significant disability, when the concept of chronic sorrow is the primary focus of this case study research?

Central Prompts**:** The following prompts were used to guide rather than direct the interviews:

1. Parental reaction to the medical diagnoses of their child.
2. Parental experience of the loss or delay of their child's developmental milestones.
3. Parental experience of raising children who have a significant disability alongside children without special needs.
4. Parental experience of marriage or being single while raising a child with a significant disability.
5. Parental experience of support from extended family.
6. Parental sense of loss of self over time.
7. Parental reaction to the changelessness of their role as parental caregiver.
8. Parent's ability to discuss their child's future after the parent's death.

Trustworthiness

The researcher ensured trustworthiness of the study through four distinct ways as suggested by Schwandt (2007): credibility, transferability, dependability, and conformability. The creditability of the study was documented through the use of

information gathered through open-ended prompts as designed by this researcher who has over twenty years of personal and professional experience working in the field of disabilities. In addition, the sample was limited to those families that had a child with significant and multiple disabilities that limited the possibility of independent living.

Knowing that the participants of this study were parents of a child with significant disabilities at various stages in parental life allows for transferability (Schwandt, 2007) to a larger population because of the specificity of the design and the subjects involved. This study did not include families who have children that are able to utilize various independent life skills, but only included those families whose children will be dependent up them for the rest of the parent's life.

The dependability of the study (Schwandt, 2007) was found in the true life depictions provided by the parents as they described their experience of raising a child with significant and multiple disabilities over time and their realization or their own mortality and their need to make preparations for the continued provision and safety of their child. The concept of daily life with a child with significant disabilities is unlike that of a typical child as it includes the changelessness of the child's dependence on others.

The conformability (Schwandt, 2007) for this study was gathered from seminal research over the last forty six year regarding chronic sorrow and through the solicited feedback from research participants regarding the study findings. Although a large portion of studies have been performed in other fields of research attempting to determine if chronic sorrow is a different experience than that of grief and mourning. This study

looked at the concept of chronic sorrow as a different experience from that of grief and mourning and to expand the concept to describe the experience of parenting a child with significant and multiple disabilities across the lifespan.

Procedures

Self of the Researcher

This researcher is the mother of a 25 year old son who has significant disabilities. Parenting a child with significant disabilities and working within the field of disability service delivery and community mental health has provided the researcher with insights and knowledge concerning the life lived by other parents in similar situations. The researcher's family experience was considered to be an asset when interviewing parents for the study as the level of trust and understanding for the experience of Chronic Sorrow was understood from the viewpoints of both a professional and parent. Self- disclosure regarding her son was provided to participants at the start of the interviews during the review of consent forms and counseling resources as well as the purpose of the study.

Data Analysis Procedures

Marshall and Rossman (2005) depict the analysis portion of the study as one that allows the researcher to take reams of data and reduce it down to manageable chunks. Immersion in the data that is compiled was achieved by reading and rereading the transcribed responses from the interviews. The researcher listened to the audio taped interviews and transcribed each interview in its entirety, first through hand written transcription and then transferred the handwritten transcriptions to word-processed document. At the time of transcription, the primary researcher assigned pseudonyms to

the parent participants to maintain confidentially with the additional thought having a name attached to each of stories obtained through the interviews would keep the stories more personal.

Johnson (1997) defined theoretical validity as the degree of theoretical explanation, credibility and defensibility the data provides (p. 162). Yin (2003) described a holistic approach to case study research which examines entire cases and then presents descriptions, themes and interpretations or assertions related to the cases presented in the research. The analysis of the data from this research methodology was accomplished through the identification of specific themes related to the experience of chronic sorrow. The researcher coded the transcribed data collected during the audio taped interviews of the seven parents into four groups of ideas which provided support for the themes related to the chronic sorrow phenomenon, the life cycle transitions associated with the ebb and flow of the experience as well as the resilient strengths exhibited by families across the lifespan.

The primary researcher recruited the dissertation advisor to code several of the interviews and then again to randomly test the researcher generated themes for the purpose of enhancing validity. Throughout the coding process the primary researcher and advisor met to discuss the individualized results of the coding for the interviews of Cassie, Cathy and David. The research team decided on nine primary themes: (1) reaction to the diagnosis, (2) barriers (medical and informational), (3) adjustment (spousal, family, siblings extended family, (4) resiliency, (5) supports (extended family and community), (6) hope, (7) future, (8) chronic sorrow, and (9) individual adjustments.

The main concern and endeavor in this study was to provide true depictions of the thoughts, feelings and any other emotions expressed by the parent participants.

The effort to move the description of the construct of Chronic Sorrow past the idea of a grief model and into a conceptualization of an ongoing and continual loss, the primary researcher and dissertation advisor took the nine themes and reviewed the goals outlined by Boss (2006) in her explanation of Ambiguous Loss in The Contextual Model of Family Stress. This process helped to determine whether any of the identified themes would fit within the components of the construct of Ambiguous Loss and Boundary Ambiguity to further simplify the explanation of the 9 themes as well as to consider the possibility of the expansion of Ambiguous Loss and Boundary Ambiguity to families who have a child with significant disabilities in to the application of The Contextual Model of Family Stress Theory. The decision to integrate the therapeutic goals found in the constructs of Boss'(2002) expansion of The Contextual Model of Family Stress Theory, (Ambiguous Loss and Boundary Ambiguity) into the coding process of this research study would provide the development of categorical themes that could help bring understanding to the construct of Chronic Sorrow and its characteristics of the ebb and flow across the lifespan of the parent.

The researcher also employed member checking of the data with the study by asking the participants to "solicit feedback on the researcher's findings (Schwandt, 2007 p.187). This step is important in corroborating the existence of the chronic sorrow phenomenon and its link to the family life cycle stages as it was hypothesized by the researcher. Participants were emailed a copy of the transcribed audio taped interviews

and asked to review the contents to determine if the transcription process and interview had captured their stories accurately. The participants were given five days to review the transcribed interviews and return the documents back to the primary investigator with any notations they wished to have added for clarity. At the end of the five day period, five of the eight participants contacted the researcher through email replying their agreement with the contents of the transcribed interview without changes. The researcher did not receive any response from the other two participants regarding their transcribed interviews.

Limitations

This study is limited because the eight participants were drawn from North Texas and the sample size was small. The original proposal had proposed collecting interviews from eight to 12 parents but sampling was stopped when saturation was reached. Using one agency website to collect potential participants did not prove to be successful. Performing the study on a larger scale with the help of more service providers who work specifically with families who have children with disabilities may have brought more participants into the study. The study included a larger proportion of Caucasian participants; African Americans were not represented in this sample.

The majority of the families who participated included input from mothers of children with significant disabilities. The inclusion of the perspective of more fathers would have revealed a more inclusive discourse regarding their perception of parenting. The study participants had a greater majority of boys (n=6) with significant disabilities and only one girl.

Summary

Across all parental experiences, the researcher asked whether parents experienced chronic sorrow or what other emotion accompanied important life events as well as other events related to their other children, their work, and their marital relationship. The research study collected information through the use of audio taped, semi structured, open ended interviews. The information and data gathered was analyzed for themes concerning the ebb and flow of the chronic sorrow phenomenon as it is experienced across the family life cycle. This intrinsic case study research involved investigating the chronic sorrow phenomenon from multiple parental perspectives at differing stages or points within the life cycle. Finally, parents were also asked to look into their future and consider what other events such as their own changes due to the aging process affected their experience of chronic sorrow. The researcher asked questions to guide parents past the rehearsed story of their lives into a conversation of feelings, losses, hopes, dreams, expectations, and realities -- all helped to develop specific themes concerning chronic sorrow.

CHAPTER IV

RESULTS

Introduction

The coding process elected for use in this research study involved the primary researcher and dissertation advisor separately reading the transcribed interviews of the participants and individually identifying the salient themes found in the transcripts. The research team met periodically to discuss the similarities and differences found in the researcher derived themes and those of the Contextual Family Stress Theory of Boss (2006). The researcher derived themes decided upon were *Initial Reaction of Chronic Sorrow to the Diagnosis, Normalizing the Ambivalence of Parenting* and *Ambivalence about the Future.* The themes adopted from Boss (2006) and her description of Ambiguous Loss used in the description of the themes found in the transcripts were *Finding Meaning, Tempering Mastery, Reconstructing Identity and Discovering Hope.*

The researcher derived themes were used to describe the experiences related to the concern of parents for the delayed development of their child, the search for professional intervention and subsequent diagnosis and the reaction to the news of the diagnosis of disability by the parents. In addition to the diagnosis the themes were also derived to assist with the explanation of the experience of parenting a child with significant disabilities and the resulting ambiguity found in this experience which encompassed the thoughts and feelings surrounding the unknown expectations for the life of the parent and for that of the child diagnosed with the disabilities. The final researcher

derived theme was utilized to bring awareness to the thoughts for the future of the parents and the child, specifically how this would or would not be planned for, the questions surrounding life for the child after the parent becomes unable to continue care due to illness or death.

The adopted themes of Boss (2006), and her description in the concept of Ambiguous Loss were used to aid in bringing about understanding to the themes relating to parents ability to find meaning for the life that they are living with their child who has significant disabilities. The themes relating to developing and maintain the skills needed to provide a life with the new normal of a child with disability as well as the themes describing locating an identity outside the label of a parent of a child with disability to the location of hope within this process were all found to fit within the constructs of Ambiguous Loss.

Participants

This qualitative sample consisted of one couple, five married females and one divorced, single female parent. The races represented in the sample were Caucasian (71.4%), Hispanic (14.2%), and Asian (14.2%). All participants are the biological or adoptive parents of children whose disability is significant in nature and the probability of independent living for the child later in life will not be possible. The groups of children with significant disabilities discussed in the face to face interviews included seven males and one female. The Parent Participant Table provides a more complete demographic information, family life cycle stage and specific diagnoses for each child.

The researcher coded the transcribed data collected during the audio taped interviews of the seven parents into four groups of ideas which provided support for the themes related to the chronic sorrow phenomenon, the life cycle transitions associated with the ebb and flow of the experience as well as the resilient strengths exhibited by families across the lifespan.

The primary researcher recruited the dissertation advisor to code several of the interviews and then again to randomly test the researcher generated themes for the purpose of enhancing validity. Throughout the coding process the primary researcher and advisor met to discuss the individualized results of the coding for the interviews of Cassie, Cathy and David. The research team decided on nine primary themes: (1) reaction to the diagnosis, (2) barriers (medical and informational), (3) adjustment (spousal, family, siblings extended family, (4) resiliency, (5) supports (extended family and community), (6) hope, (7) future, (8) chronic sorrow, (9) individual adjustments. The main concern and endeavor in this study was to provide true depictions of the thoughts, feelings and any other emotions expressed by the parent participants and the decision to integrate the therapeutic goals within the coding process of this research study would achieve this goal but providing categories that would help bring understanding to the concept of Chronic Sorrow and its characteristics of the ebb and flow across the lifespan of the parent.

The primary researcher considered Boss's (2006) Contextual Model of Family Stress Theory to reexamine the definitions of stressors to determine if Chronic Sorrow could be an addition to the internal stressors as explained by the theory. Boss (2006)

described a chronic stressor as a "situation (as opposed to an event) of disturbed equilibrium that persists over a long period of time (p.54). Since the definition of the concept of Chronic Sorrow has been defined by Olshansky (1962) and this researcher as one that continues across the lifespan of the parent and is characterized by the ebb and flow of its intensity based on the specific maturation process of the family according to the Life Cycle Stages of McGoldrick & Carter (1980), it was determined that Chronic Sorrow could be viable addition to the Family Stress Theory.

The research team then discussed whether or not Chronic Sorrow was the same as Ambiguous Loss. The construct of Ambiguous Loss contains two distinctions: (1) the situation is ongoing but the primary component of the situation is either psychologically present and physically absent or physically absent and psychologically present; (2) the facts regarding the situation are difficult to locate which thereby creates the ambiguity in being able to apply closure to the situation. Chronic Sorrow is an experience that can be defined as ambiguous at the initial time of the diagnosis due to the significant unknowns related to the diagnosis just received by the parent is a relational disorder as the parent must adjust to not parenting the expected child and could also be classified as an internal chronic stressor since it is characterized by its existence throughout the lifespan.

To assist with the explanation of the addition of Chronic Sorrow as a special case of Contextual Model of Family Stress, the researcher used the therapeutic goals described by Boss (2006) as part of the construct of Ambiguous Loss to underscore the distinction of Chronic Sorrow as a chronic internal stressor. It is the hope of this researcher that such an expansion of the model will enable further applicability of the

Family Stress Theory to families who have children with significant disabilities. The therapeutic goals outlined by Boss (2006) in relation to Ambiguous Loss and Boundary Ambiguity were found to be applicable to the research themes found in the interview transcripts of the this study.

The primary researcher and dissertation advisor proceeded to read each interview separately to identify specific themes and categories prevalent in each transcript. The researcher looked for salient themes, ideas, languages or beliefs that may surface as a reoccurring phenomenon. Further discussion regarding the therapeutic goals outlined by Boss (2006) in relation to Ambiguous Loss and Boundary Ambiguity were found to be applicable to the research themes found in the interview transcripts of this study and were revised to add to the description of the experiences of parents who have a child with significant disabilities

The following themes included the researcher derived themes of *Initial Chronic Sorrow Reaction to the Diagnosis, Normalizing the Ambivalence of Parenting,* and *Ambivalence about the Future* and the four adapted themes from Ambiguous Loss (Boss, 2006) of *Finding Meaning in an Overwhelming Situation, Tempering Mastery Parenting a Child with a Disability, Parents Restructure their Identity, and Discovering Hope in the Redefined Family.* Definitions of the seven themes are provided to allow the reader to understand how each of these themes depict the unique experiences of parents who have children with significant disabilities and further define the Chronic Sorrow experience theorized by Olshansky (1962):

- *Initial Chronic Sorrow Reaction to the Diagnosis,* theme 1, has been defined by the research team to include the beginning process of searching for the diagnosis after noticeable signs of delay or missed milestones of development in the child were relayed to professionals by parents and the subsequent reaction to the diagnosed disability. Olshansky (1962) described the Initial Chronic Sorrow Reaction to the diagnosis as a "deep symbolism buried in the process of giving birth to a child with a disability combined with the permanent day by day dependence and interminable frustrations resulting from the child's disability joined together to produce the parent's chronic sorrow"(p. 192).
- *Finding Meaning in an Overwhelming Situation* (Boss, 2006) theme 2, is defined as the journeys parents take to find the meaning in their life since the diagnosis, both for the child with the significant disabilities and for themselves as individuals. Olshansky (1962) discussed this as a process where "many parents may need to discuss their feelings and the problems associated with a child with a significant disability on many occasions" (p. 193).
- *Tempering Mastery of Parenting a Child with a Disability* (Boss, 2006) theme 3, was used to capture the process parents began and continued to work toward as mastering the things needed to make sense of the job as a parental caregiver of child with significant disabilities. It is this theme that Olshansky (1962) described as the process where "parents will increase their comfortableness in living with and managing a child with significant disabilities" (p. 193).

- *Parents Restructure their Identity* (Boss, 2006) theme 4, was used to identify some of the steps parents have taken to become more individualized in their lives aside from the role of constant caregiver or perpetual parent. Olshansky (1962) viewed this theme as the "opportunities parents should take and be given to be away from their child at recurring intervals to get relief and enhance comfortableness" (p. 193).
- *Normalizing Ambivalence of Parenting*, theme 5, a child with significant disabilities was used to share the struggles parents encounter even after they have received the diagnosis in relation to the uncertain future for themselves and their child. This theme was described by Olshansky (1962) as the opportunity for parents to vent and clarify feelings and to receive legitimacy for the feelings they are experiencing, which can in turn facilitate adaptation to the chronic sorrow experience as the new normal in the family (p. 192 & 193).
- The theme of *Discovering Hope in the Redefined Family*, (Boss, 2006) theme 6, was used to describe the process in which parents find ways to manage their lives with their "normal" of having a child with significant disabilities and the process that transpires to reach this point. Olshansky (1962) proposed this process would help parents to achieve the goal of being comfortable with the reality that their child has a significant disability and with that diagnosis comes the experience of chronic sorrow but it is a manageable chronic stressor (p. 193).
- *Ambivalence about the Future*, theme 7, was used to describe the sense of confidence in knowing their child as an individual and as an individual with a

disability; a sense of uneasiness when considering the future of the child and addition to the worries of who will care for them when the parents are no longer able to because of health or death.

Theme Discoveries

This qualitative case study used non-directive central prompts to gather information about the parents' experience of chronic sorrow over the lifespan of their child who has been diagnosed with a significant disability. Parents were asked to share their initial reaction to how and when they received the diagnosis concerning their child as well as their unique family and parental experiences of their child's development in terms of the loss or delay in achieving expected developmental milestone. The open ended questions were used to help the researcher move parents passed their rehearsed stories that are often told to acquaintances and friends and onto thick descriptions of how their lives have been transformed since receiving the diagnosis of significant disability for their child. The thoughts and words of the eight parents will be shared below according to the three themes developed by this researcher and four adapted themes developed by Boss (2006) listed above, starting with the parent of the youngest to the oldest child.

Initial Chronic Sorrow Reaction to the Diagnosis

Theme one is defined in two parts by this researcher: the *initial realization* that their child not meeting the developmental milestones and the *parental reaction* to the often multiple and then final diagnosis. The *initial realization* can be described as the parents' experience of searching for a firm diagnosis after the parents noticed signs of delay in their child's expected developmental milestones or their child had unusual behaviors or

medical conditions that caused to parents to continue to seek professional help. The *parental reaction* can be described as the ongoing parental reaction the often multiple diagnoses that the parents receive from a variety of medical professionals and their subsequent reaction to what appears to be the final diagnosed disability. The following concepts from the parental transcripts illustrate this theme.

- Cathy (34) and David (38), parents of a 31/2 year old son diagnosed with Fragile X Syndrome share the following:

  > Our pediatrician wanted to take a wait and see approach; we just wanted her to do more. We had him a year and nine months before a diagnosis.
  > I was waiting on something I just didn't know what. There was probably more of mental shock going on just trying to comprehend the news.

- Nancy (27), mother of a 7 year old son with Significant Multiple Disabilities reported:

  > I found out there was a problem when I was about 20 to 22 weeks. They didn't know what the implications would be and they didn't know if he would survive the rest of the pregnancy or even childbirth.

- Cassie (39), mother of a seven and half year old daughter diagnosed with Angelman's Syndrome stated:

  > The day they told us something was really really wrong, she was about 9 months. She had started missing a lot of milestones. I mean it was just so devastating. This is huge, it weighs heavy.

- Denise (54), mother of an eighteen year old male diagnosed with Fragile X reported:

  > We had to find out what it is cause he can't tell us. We were shocked and didn't understand at that point. Simple things that would not seem big would be devastating as far as in the pit of stomach.

- Ruth (40), mother of two adult males, (26, and 25) diagnosed with Fragile X, Autism and Tourettes Syndrome stated:

People thought something was wrong with me cause I kept saying something was wrong with my boys. I felt trapped.

- Maria (51), mother of a 29 year old male diagnosed with Mental Retardation and Autism reported:

  When I found out his diagnosis I was so young. I was 27 years old and he is my first child so I did not know what in the world they were meaning about Autism. I was confused. I did not know what questions to ask.

- Lisa (70), mother of a 30 year old diagnosed with Autism and Seizure Disorder stated:

  It was a challenge for me, I keep going on. I'm upset not because something wrong, I had to fight to find a solution.

Finding Meaning in an Overwhelming Situation

Theme two is defined as the ongoing internal journey parents take to find the meaning in their life following the diagnosis – meaning for both their child and for themselves as individuals.

- Cathy (34) and David (38), parents of a 31/2 year old son diagnosed with Fragile X Syndrome report:

  I read everything. We work around it as best as we can. These are the cards I have been dealt. I think it helped bring us closer, we work harder to not let our marriage fail. It's given us a purpose in our marriage.

- Nancy (27), mother of a 7 year old son with Significant Multiple Disabilities stated:

  I keep everything from all the diagnoses, test and procedures about his medical history on a flash drive and have printed copies. I keep a list of his disabilities with the implications that follow him wherever he goes.

- Cassie (39), mother of a seven and half year old daughter diagnosed with Angelman's Syndrome shared the following:

We never received a diagnosis in black and white, we had 8 different diagnosis of what they thought she had, and they were matter of fact without follow up.

- Denise (54), mother of an eighteen year old male diagnosed with Fragile X reported:

I just go through a tsunami of feelings and it was overwhelming. That's when we started to grieve for the child we didn't have and dealing with that and learning to cope with it.

- Ruth (40), mother of two adult, (26, 25) males diagnosed with Fragile X, Autism and Tourettes Syndrome stated:

"We went to countless numbers of doctors but all of them just said they were boys and I was overreacting. No one would listen.

- Maria (51), mother of a 29 year old male diagnosed with Mental Retardation and Autism reported:

"I would go to the library and get the books I needed, bring them home and read and read I kind of trained myself. I had to quit college.

- Lisa (70), mother of a 30 year old male diagnosed with Autism and Seizure Disorder stated:

"I did not know because we did not ever get the diagnosis until he was 15 years old. I treat him like a normal child, he travelled with me.

Tempering Mastery of Parenting a Child with a Disability

Theme three was used to capture the process rather than the journey, parents began and continued to work out currently as they learn to master the challenges and tasks, so that they can make sense of their job as a parental caregiver, and provide the optimal care needed by their child with significant disabilities.

- Cathy (34) and David (38), parents of a 31/2 year old son diagnosed with Fragile X Syndrome stated:

It's not as bad as you think. You're going to go from this joyous level up here you know 180 degrees to complete nothing down here. You're still going to love the kid and have many moments of joyous celebrations.

- Nancy (27), mother of a 7 year old son diagnosed with significant multiple disabilities reported:

This is all too much and always I have the thought of what if I screw up and something I should have done and he is sick from it.

- Cassie (39), mother of a seven and half year old daughter diagnosed with Angelman's Syndrome stated:

I'll be alright; I have this conversation with myself everyday or every night about 2 am when I can't go to sleep.

- Denise (54), mother of an eighteen year old male diagnosed with Fragile X shared the following:

I mean after I got over the grief of the child I wasn't going to have and knew and came to grips with the fact that he was a gift, he was still a child, he was still my child, there was not planning in this, we didn't do this, this happened for a reason.

- Ruth (40), mother of two adult males, (26, and 25) diagnosed with Fragile X, Autism and Tourettes Syndrome reported:

I wanted someone to tell me what life was going to be like in the future. I wanted someone to tell me what life was going to be like now, I wanted someone to tell me is my life going to suck, are we going to have a decent life, but no one could tell me that.

- Maria (51), mother of a 29 year old male diagnosed with Mental Retardation and Autism reported:

My son taught me how to be patient. I have a lot of potential. I will be the best mom that my son can have and maybe that is what is important.

- Lisa (70), mother of a 30 year old male diagnosed with Autism and Seizure Disorder reported:

This is a lifetime, you have to be strong and care for him, we have to have an attitude to believe and to try, it is so important.

Parents Restructure Their Identity

Theme four was used to identify some of the movement parents have taken to become or maintain a separate identity from their child rather than becoming caught up in the role of constant caregiver or perpetual parent.

- Cathy (34) and David (38), parents of a 31/2 year old son diagnosed with Fragile X Syndrome reported:

  I think it has made us stronger (as spouses). I think it has helped bring us closer. It's a better vehicle for communication, we are a unified front.

- Nancy (27), mother of a 7 year old son diagnosed with significant multiple disabilities shared the following:

  I learned to be his advocate because if I didn't nobody else would. My son is not broken he is just different. He has made me stronger.

- Cassie (39), mother of a seven and half year old daughter diagnosed with Angelman's syndrome stated:

  I went back to church. I got my daughter in a special needs ministry. I have become a full time parent.

- Denise (54), mother of an eighteen year old male diagnosed with Fragile X reported:

  I just needed to go back to me because I was so overwhelmed. When I'm overwhelmed I had to look to find what it is that will cause me to be filled up again.

- Ruth (40), mother of two adult males, (26, and 25) diagnosed with Fragile X, Autism and Tourettes Syndrome stated:

I have a lot to offer people, the kid's have a lot to offer people, but the bottom line is life goes on. Their hearts and souls are just so beautiful.

- Maria (51), mother of a 29 year old male diagnosed with Mental Retardation and Autism reported:

Maybe it is not important that I make $100,000 a year but that I understand that my son is here for a reason and given to me to for a reason to be a better person and to help others.

- Lisa (70), mother of a 30 year old male diagnosed with Autism and Seizure Disorder

My husband tells me we are so lucky to have our son because the child is like God because he has taught us so much. I know I have to be strong.

Normalizing the Ambivalence of Parenting

Theme five can be described as the struggles parents encounter even after they have received their child's diagnosis when they struggle to manage their understanding and emotional reaction to an uncertain future for both themselves and their child.

- Cathy (34) and David (38), parents of a 31/2 year old son diagnosed with Fragile X Syndrome reported:

What is his future? This is what it is and he is only going to get worse as he get older. There are times when I'm changing his diaper that I get angry about it, like I just want this kid to go on the potty. I don't know whether to scream or to cry. (

- Nancy (27), mother of a 7 year old son diagnosed with Significant Multiple Disabilities stated:

Really whenever they threw things out there about my son, I just researched everything. I didn't take much time to think about anything except what is this, and what is the best course of action.

- Cassie (39), mother of a seven and half year old daughter diagnosed with Angelman's Syndrome reported:

Well I never thought that I would be taking care of someone forever. She will still irritate me and make me happy. I still don't even know her.

- Denise (54), mother of an eighteen year old male diagnosed with Fragile X Syndrome reported:

I began to understand what I got, meaning what my son had and what I got as a parent. I just go through this tsunami of feelings and it was overwhelming.

- Ruth (40), mother of two adult males, (26, and 25) diagnosed with Fragile X, Autism and Tourettes Syndrome shared the following:

I don't listen to people as much as I used to. I'm pretty hard core in telling people where to go quick. Way more opinionated and I don't apologize for that.

- Maria (51), mother of a 29 year old male diagnosed with Mental Retardation and Autism stated:

To this day the hardest thing for me when I had my son with a disability and my other two children was having to switch my brain from dealing a certain way with my son and to switch my brain to deal another way with my other two.

- Lisa (70), mother of a 30 year old male diagnosed with Autism and Seizure Disorder reported:

But my son have brain damage because he right now he almost 30 years old and he is like a two year old.

Discovering Hope in the Redefined Family

The final theme describes the goal in which parents are able find ways to manage their lives with their now "normal" of having a child with disabilities in such a way that the parent themselves view the future in a more positive way and see their child as having unique potential for growth and development. Every parent in this study were able to voice the achievements in this area but it is possible that these positive viewpoints can be lost due to the continued day to day struggles of living with a child who has a disability.

- Cathy (34) and David (38), parents of a 31/2 year old son diagnosed with Fragile X Syndrome shared the following:

  It's hard to be around people who don't have kids with special needs. I can't sit with my girlfriend who has a 3 year old who is writing his name and doing things when my kid can't say his name or momma for that matter.

- Nancy (27), mother of a 7 year old son diagnosed with Significant Multiple Disabilities stated:

  There have been times where I wonder where would I be if I hadn't had him but I don't stay there long. I believe my son saved me from myself.

- Cassie (39), mother of a seven and half year old daughter diagnosed with Angelman's Syndrome reported:

  It's not like when someone dies and you grieve. It's not something that goes away, it's always there.

- Denise (54), mother of an eighteen year old male diagnosed with Fragile X Syndrome stated:

  I mean after I got over the grief of the child I wasn't going to have and knew and came to grips with the fact that he was a gift, he was still a child, he was still my child, there was no planning in this.

- Ruth (40), mother of two adult males, (26, and 25) diagnosed with Fragile X, Autism and Tourettes Syndrome reported:

  There comes a point when you get tired of raising kids and it's not that I'm sick of raising my kids, it's just for the rest of my life I will be doing this.

- Maria (51), mother of a 29 year old male diagnosed with Mental Retardation and Autism shared the following:

  It's not my way, it was not my plan it was God's plan.

- Lisa (70), mother of a 30 year old male diagnosed with Autism and Seizure Disorder reported:

I feel like God teach me many things I don't know. Since I have my son, I learn more and I'm not as scared as I used to be I have changed how I think and am with others.

Ambivalence about the Future

Parents in this study were found to elicit a sense of confidence in knowing their child as an individual and as an individual with a disability. With this confidence, a sense of ambivalence was related when their thoughts regarding the future of the child was raised in addition to the worries of who will care for them when the parents are no longer able to because of health or death. This researcher believes the ambivalence lies in the thought or the presence of holding two opposing ideas or emotions as the same time. Life and death of the parent; the concerns for the child's needs and future without them; contemplation the present and the caring for a child with disabilities and at the same time wondering about the future as they age and the needed care and love their child will also need after the parents death. Since the sample included responses from parents at differing stages of the life cycle, those responses are shared below.

- Cathy (34) and David (38), parents of a 31/2 year old son diagnosed with Fragile X Syndrome shared the following:

  We are in our mid to late 30's and when we brought him home, what is his future? I mean for me I didn't think in hindsight you think about it like oh my gosh are we going to have a great retirement and do our own thing that didn't cross my mind. Like is he going to, what happens when I die? What if we don't have more kids?

- Nancy (27), mother of a 7 year old son diagnosed with Significant Multiple Disabilities reported:

  The biggest problem I have is how do you sit back and plan for such a completely uncertain future. Most children you have them and they grow up they go to

college. Trying to figure out how I'm going to care for him as he continues to grow, when I start trying to think of that, that is when it all becomes very overwhelming.

- Cassie (39), mother of a seven and half year old daughter diagnosed with Angelman's Syndrome stated:

I don't even know where to start. I mean, you don't walk around and ask typical parents what they are going to do with kids when they are 16, or 18. I really don't know what she has that we can capitalize on.

- Denise (54), mother of an eighteen year old male diagnosed with Fragile X Syndrome reported:

The majority of parent's keep their children until they are so old and can't care for them no more and then the separation takes place, which isn't fair for the child. And whatever it took for me to get over my selfishness and protectiveness needed to happen.

- Ruth (40), mother of two adult males, (26, and 25) diagnosed with Fragile X, Autism and Tourettes Syndrome stated:

I have wills, and insurance policies I pay on every month. My oldest son will always be with someone. My youngest son has the luxury of being able to function in that type of setting (group home). (Appendix L)

- Maria (51), mother of a 29 year old male diagnosed with Mental Retardation and Autism reported:

Lisa and I have talked about it a couple of times. I've told Lisa if she passes away before I do and her husband and if it is okay with them I will take care of their son.

- Lisa (70), mother of a 30 year old male diagnosed with Autism and Seizure Disorder stated:

We used to. In the last 10 years we have changed our minds. We used to think family would care for our son, now we have changed our minds.

Cultural Difference and Extended Family

Cultural differences were noted between the Caucasian, Hispanic and Asian families in regards to extended family involvement with the child with significant disabilities once a diagnosis was received. The following statements from the participants bring these differences to light when considering the interaction of extended family with the participants and their child with significant disabilities.

- Cathy (34) and David (38), parents of a 31/2 year old son diagnosed with Fragile X Syndrome shared the following:

  My sister said he's fine, like he was going to grow out of it. (Cathy)My mother said we should have adopted an American child.

- Nancy (27), mother of a 7 year old son diagnosed with Significant Multiple Disabilities reported:

  My parents have always been involved with my son and if not for them I'm not sure where I would be. They are my committee with my son.

- Cassie (39), mother of a seven and half year old daughter diagnosed with Angelman's Syndrome stated:

  My stepmom always asks about my plans for my daughter when she is 24. I can't talk about that yet, I don't know. My husband is not very close to his family at all.

- Denise (54), mother of an eighteen year old male diagnosed with Fragile X Syndrome reported:

  Well mom was a great teacher and dad had a PhD in psychology and he understood it I guess in generalities, but neither of them go the depth of what it was going to mean or could be proud of that, or of what they had.

- Ruth (40), mother of two adult males, (26, and 25) diagnosed with Fragile X, Autism and Tourettes Syndrome reported:

So as they were little it was sad, I had to deal with a bunch of people in the family and their dad's family that thought they had cooties or something. They kept saying you just need to treat them like they are normal and they will snap out of it.

- Maria (51), mother of a 29 year old male diagnosed with Mental Retardation and Autism stated:

I never had a problem with extended family. I guess they were okay because they weren't in close contact to live it every day.

- Lisa (70), mother of a 30 year old male diagnosed with Autism and Seizure Disorder reported:

My family support 100% and spoil him rotten. You know they feel that he's the black sheep for all the family; he has the support from everyone in the family.

Marital and Spousal Issues

Six of the seven participants were married, and mentioned some of the issues relating to the differences in how the news of the diagnosis was received and processed. The following statements address the affect the diagnosis and subsequent life changing events had on the marital relationship and the interactions with the spouse after the news of the diagnosis.

- Cathy (34) and David (38), parents of a 31/2 year old son diagnosed with Fragile X Syndrome shared the following:

(David) Yeah, I mean it was probably shock more than anything, I honestly don't remember because there was probably some more of mental shock going on just trying to comprehend that news.

- Nancy (27), mother of a 7 year old son diagnosed with Significant Multiple Disabilities reported:

I remarried in 2007. Having a second parent is very different because I made all the decisions before. I have someone to argue with, my husband.

- Cassie (39), mother of a seven and half year old daughter diagnosed with Angelman's Syndrome stated:

  We really had a hard time. So we almost split up and really didn't talk about her birth until 2 years after we were sitting in a lawyer's office thinking we had a case to go after the Dr.'s. This was the first time I ever knew how he felt about the whole thing.

- Denise (54), mother of an eighteen year old male diagnosed with Fragile X Syndrome reported:

  My husband, I think like typical males, 60% of all husbands leave because they can't deal with that, said ya know I'm leaving at some point.

- Maria (51), mother of a 29 year old male diagnosed with Mental Retardation and Autism stated:

  My husband was not admitting that something was wrong with his first child. He said that I was the one who was crazy and that I was the one who was psycho analyzing everybody.

Summary

The therapeutic goals described by Boss (2006) as part of Ambiguous Loss and those developed by this research have provided helpful insight to the statements given by the participants of this study. The use of these themes assisted in developing a sense of understanding of Chronic Sorrow as an internal stressor and its possibilities as a useful addition to the Contextual Model of Family Stress. The journey each parent experienced and shared revealed that the feelings of Chronic Sorrow do not end at a particular point in their life as a parent, but are felt at varying points across the parent's life span. The outlook of family life, social interaction, connection to others, cultural implications as well as marital and spousal relationships are impacted by the internal stressor and play an important role in the position as parental caregiver to a child with significant disabilities.

CHAPTER V

DISCUSSION

> "Most parents who have a child with significant disabilities suffer from a pervasive psychological reaction, chronic sorrow that has not always been recognized by professional personnel who attempt to help them" (Olshansky, 1962, p. 190).

For centuries, parents have experienced the birth of children with multiple and severe disabilities, but for many families, their child did not survive. In more recent times, medical science and determined parents have increased the probability that these same children will survive and be with their families for many years. The realization that they now have a baby or child with significant disabilities can leave parents with numerous questions and few answers. It is the disparity between available medical and developmental information for the child, altered expectations about how to parent a child with significant disabilities, and the child's increased and chronic need for care that submerges parents in an unyielding experience of emotions and reactions that ebb and flow over time. Olshansky (1962) believed that chronic sorrow was a phenomenon that best describes the experience that parents have over their life course as they raise a child with significant and severe disabilities. He encouraged helping professionals to accept two ideas when helping parents: (a) professionals needed to accept parents the way that each parent was experiencing their child at that moment; and, (b) that parents needed to be seen as individuals experiencing a normal reaction to a tragic event that was happening in the life of the child, the parents, and the family. In this present study, the

researcher focused on the experience of the adult as they first learned that they had become the parent of a child with a significant disability and, then, how the parents reported that experience over their lifespan as the child's level of dependence remained unchanged across multiple developmental stages and changes. When the parents in this study realized that their child's level of dependence would remain at a high level for the rest of the child's life, the parent was initially overwhelmed by the changelessness of their situation. The changelessness of the parenting role combined with the duties of caregiver, protector and decision maker has continued for these parents for as many as 30 years and will end only with the death of the parent or the child. This experience of unending sadness that ebbs and flows throughout lives of the parents in this study supports Olshansky's concept he termed chronic sorrow.

Caring for Children with Significant Disabilities

The early 1900s brought the practice of removing children who had disabilities from their home because the societal belief was that it was the best practice to "break the connection between poor parents and child with disabilities to allow the professionals to assume the parental role in asylums and reform schools" (Ferguson, p. 126, 2002). This medical model "best practice" supported the notion that parents would not be able to care for and withstand the sorrowful feelings associated with having a child with significant disabilities. Farber concluded in several studies in the early 1960s that it was a common practice to institutionalize children with significant handicaps as the medical community believed that the family's ability to raise a child with disabilities led to problems in the family system, family dependency upon community resources, and the family lacking

sufficient financial resources. Solnit and Stark (1961) concluded that the level of grief and mourning experienced by the parents of a child with significant disabilities would prevent the process of normal development in the rest of the family system.

Conversely, the eight parents in this present study reported that they did briefly wonder how they could provide sufficient care for their child and seven of the eight had never entertained the notion that they would give up caring for their child and send their child to an institution. One parent of two adult males diagnosed with significant disabilities placed her youngest son (25 years old) in a group home due to behavioral issues and the lack of support with the hope that he would be taken care of and be happy in this setting. After a six month stay, she weighed the costs of this decision and brought him home due, in part, to the level of care he was receiving in personal hygiene and safety issues relating to the group home staff to client ratio. The most significant reason she brought him back home was the belief that he belonged with family where he could receive more individual care and affection. The other parents were adamant that their child belonged with the other members of the immediate family; several parents remarked on how other siblings provided care for their brother or sister and had shared how much they had learned from this experience.

Olshansky (1962) described the parent's reaction of Chronic Sorrow following their child's diagnosis of significant disability as a "deep symbolism buried in the process of giving birth to a child with a disability combined with the permanent day by day dependence and interminable frustrations resulting from the child's disability joined together to produce the parent's chronic sorrow" (p. 192). Each parent's association with

the experience of Chronic Sorrow created the opportunity for growth and adaptation to the role of parent/care-giver and the child's ongoing needs related to the disability. According to Olshansky, the parent is challenged to not only accept the disability, but even more, faces the challenge of accepting their role as long term caregiver and the realization that they are now parents of a child with a disability. Parents face a continual process of moving through their lifespan experiencing the ebb and flow of chronic sorrow that accompanies their transformation from a parent who will launch their child around the age of 20 years to a parent who will remain a lifelong caregiver. This experience can be categorized as a Chronic Stressor that ceases ultimately at the death of the parent or at the death of the child. It is a process that becomes this particular family system's 'normal.'

Themes of Chronic Sorrow

This research study employed several of Boss's (1999) therapeutic goals outlined in relation to Ambiguous Loss and Boundary Ambiguity to further explain the concept of Chronic Sorrow. Boss (1999) viewed this type of event as one that fits into the characteristics of Ambiguous Loss because it is "an incomplete and uncertain loss" (p. 3) and as one that alters the relational process that has just begun between parent and child. Since this researcher theorizes that Chronic Sorrow is present across the life span of the parent, it is important to be able to outline a process to describe what parents may be working through as they age along with their child who has significant disabilities. The themes are used only as a way to provide a description of the parental experience of having a child with significant disabilities and are not considered to be taken as a stage

model. This researcher believes that the seven themes listed below may reoccur often over the lifespan as new information about the disability is learned and as the parents become more fully aware of what the disability will mean in the long run for themselves and their child:

The Initial Reaction of Chronic Sorrow to the Diagnosis

Finding Meaning in an Overwhelming Situation

Tempering Mastery of Parenting a Child with a Disability

Normalizing the Ambivalence of Parenting

Parents Restructure their Identity

Discovering Hope in the Redefined Family and

Ambivalence about the Future.

The Initial Reaction of Chronic Sorrow to the Diagnosis

The theme conceptualized by this researcher as the Initial Chronic Sorrow Reaction to the Diagnosis, was defined in two parts: the *initial realization* that their child is not meeting his/her expected developmental milestones and the *parental reaction* to the often multiple provisional diagnoses given by different medical professionals to their child and, then, the final diagnosis. The *initial realization* described the beginning experience of parents as they searched, sometimes for years, for a firm diagnosis after the parent noticed an undeniable sign of delay in their child's expected developmental milestones and/or their child had unusual behaviors or medical conditions that caused the parents to seek professional help beyond a visit to their pediatrician. The *parental reaction* can be described as the ongoing parental reaction to the often multiple and

provisional diagnoses that the parents receive from the many medical professionals they are referred because the diagnosis cannot be clearly made and then the parent's reaction to what becomes the final diagnosed disability. The research participants in the study voiced they felt the information they received regarding the often conflicting diagnoses did not help with their questions and concerns, but instead added to feelings of confusion, the fear of the unknown as well as the sorrow linked to this experience.

Parents in this study expressed difficulty with comprehending their child's final diagnosis as well as feelings of shock, feeling overwhelmed at the thought of their child having a permanent, disabling condition, and the overwhelming desire to understand what was happening. One mother (age 34) explained her initial reaction: *"We were shocked; I mean I thought maybe he had a brain tumor or maybe he has mild autism on the autism spectrum. I didn't expect a genetic; I didn't know what Fragile X was."* In varying degrees, every parent in this study was stripped of their belief and expectation that their child's development would follow a typical developmental course; in every case, the parent had to find both new meaning and a completely different definition of parenting and child rearing for their unique child. This same mother (age 34) described her parental reaction: *"I mean it was devastating. You know it's not like – oh, then, maybe we will work on this and there is medicine for this. You know we didn't expect like a lifelong."*

Finding Meaning in an Overwhelming Situation

The research theme of *Finding Meaning* was described by Boss (2006) as the ongoing internal journey parents took to find the meaning in their life following the

diagnosis – meaning for both their child and for themselves as individuals. Olshansky (1962) discussed this as a process where "many parents may need to discuss their feelings and the problems associated with a child with a significant disability on many occasions" (p. 193). Participants in this study explained that the motivation to begin to know the child that they realized that they now had was of utmost importance as they began a new effort to understand what the diagnosis would mean for themselves and for their child. The process of becoming consumed with the diagnosis and information gathering was seen as part of the needed skills that parents of children with significant disabilities would need to hone as they sought the optimal services for their child. Yet, it is this process that has been seen by professionals as a practice parents use to deny or delay (Solnit and Stark, 1959) acceptance of the reality of the disability.

This researcher expanded Boss's theme of *Finding Meaning* to include the emotional experience of parents being overwhelmed by the enormous changes in their lives following receipt of the child's first or final diagnosis. This theme describes the process of growth in which the parents were learning to turn their feelings of shock, their sense of being overwhelmed, and their feeling of the loss of control over their child's very delicate health situation into a future of advocacy and search for services. It is important to realize that as the parent is moving forward to understand what a diagnosis of significant disability means -- that same parent is also experiencing chronic sorrow for the expected life experience that is now gone forever. This sense of chronic sorrow lies just below the surface of the parent's awareness; they are so busy taking care of their child that they often choose to ignore their own feelings of sadness. Parents described

their efforts of locating someone to tell them what to do next or what to expect next as a primary concern, because in one moment words spoken by medical professional had completely changed their life forever. Another mother(age 54) said: *"I've always been a why person, I had to know the why to understand and cope and deal with what I 've got, and so I went down to the med school and got on the computers and tried to understand what Fragile X was."* Parents felt that all their former preconceptions of parenting and child rearing were no longer applicable in their present situation and time. Truly, it seemed to be a time when parents began to design a unique family system and culture that is known only to a family with a child who has significant disabilities.

Tempering Mastery of Parenting a Child with a Disability

Several researchers suggest that the initial grief that a parent of a child with significant disabilities experiences follows a stage model that will eventually lead into a non-grief stage (Young, 1977). Young described the process associated with parenting a child with significant disabilities as a stage process of "parental distress" (p. 41). Young suggests that parental distress leads to only two outcomes: one situation ends in the parent adapting to living with a child with significant disabilities or, in the second situation, the parent does not adapt and this maladaptive outcome is resolved ultimately in the death of the child or the parent. Bristor (1984) later proposed a wholistic model for parental grieving for their child with disabilities that were parallel to those of Kübler-Ross (1969) with the final stage described as "transcending the loss" (p. 29) and moving on with life. The stage models of all three researchers neglect the chronic aspect of grief

suggested by Olshansky which has been verified by the qualitative interviews conducted by this researcher which illustrate the ebb and flow of grief in the lives of eight parents.

Olshansky (1962) viewed this experience of chronic sorrow as a time when "many parents may need to discuss their feelings and the problems associated with a child with a significant disability on many occasions" (p. 193). The theme *Tempering Mastery* (Boss, 2006) captures the process parents begin at the time of diagnosis and continue over their lifetime as they work toward the mastery needed to make sense of the job or role as a parental caregiver of child with significant disabilities. This researcher expanded Boss's theme to emphasis the immediate focus by parents on their learning how to care and parent their child. One mother (age 39) stated: *We have so many different diagnoses that I look at her half the time and wonder what do you get, what do you see, what do you get, what do you understand. Because it's not Autism, it's not this or it's not that; nobody has really put their finger on it yet."* The parental descriptions of how they dealt with their grief included this process of mastering the changes in their lives: first, accepting own internal mandate to grow up and just do it; mastering the art of patience as their child struggles to communicate; managing a daily struggle to find a strength to provide care for their child; and finally, their growing comprehension that this experience will last throughout the parent's lifetime. This entire process describes what Olshansky identified as Chronic Sorrow.

For the majority of parents in this study, those feelings of never-ending patience and an overwhelming sense that this will never end, were compounded when the child's significant disability included few skills in verbal communication. Many parents realized

that they only way they would ever be able to communicate with their child would be through nonverbal cues or limited sign language. Parents worked hard to learn to read the nonverbal cues of their child; these same parents learned that caretakers and other professionals would need to be educated about their child if those adults were to be positive influences in their child's life. One mother (age 39) shared: "*I still don't even know her, I mean yeah... I mean that is still so hard for me, you know, but there is that half our window where she will actually look at me and she'll shake her head yes and no and she'll listen to me and it's crazy but it is that little period of time everyday where I think maybe we get each other and she knows how much I love her....*". Learning to become 'okay' with having a limited interaction with one's child is an ongoing part of the Chronic Sorrow experience. For the vast majority of parents that have children with mild disabilities or even no disabilities, they embrace the expectation that the continual care-giving process of infancy will decrease as their child develops language skills and those physical skills associated with development, such as self-help skills. In these interviews, parents recounted those developmental milestones that were never completed or only partially met, as day by day, parents continue to function in a parental role for their aging child. It is what Jennings (1984) described as perpetual parenting and Olshansky (1962) viewed as the changelessness of the parenting process and the continual dependence of the child for care and supervision.

Normalizing the Ambivalence of Parenting

Wikler, Waslow and Hatfield (1981) recommended that a continuum of services across the lifespan should be provided to parents who have children with significant

disabilities. Burke (1989) and Burke, Eakes and Lindgren (1992) explained that life with a child with significant disabilities includes a form of unresolved non-pathological grief and the necessity to provide specific ongoing support measures to assist parents in this process of parenting. Hobdell et al. (2009) stated a high level of chronic sorrow at the time of the initial diagnosis and that the experience of Chronic Sorrow remained constant in the years following. Olshansky (1962) suggested that the process of living with a child who has a significant disability involves changes, routines and discoveries of additional limitations placed on the parent's life as well as for the child and is in essence an ongoing experience of Chronic Sorrow which follows the course of the life span of the parent and the child. Olshansky viewed new realizations and reactions by the parent about their child's prognosis as a natural reaction to a tragic fact and described it as "a pervasive psychological reaction, chronic sorrow that has not always been recognized by professional personnel who attempt to help them" (p. 190).

From the interviews in this study, this researcher identified the theme *Normalizing the Ambivalence of Parenting* as a way to describe the struggles parents encounter even after the diagnosis as they endeavor to manage the emotional reaction to an uncertain future for themselves and their child. This action was described by Olshansky (1962) as the opportunity for parents to vent and clarify feelings and to feel their own sense of legitimacy for the feelings they were experiencing, which can, in turn, facilitate their adaptation to the chronic sorrow experience as the 'new normal' in the family (pp. 192-193). This researcher viewed this theme as a transitional point in a parent's life when they begin to come to terms with the still unknown outcomes of their child's disability.

The parents realize that a diagnosis is only a label with characteristics that do not provide direction about how they are to parent a child who has significant disabilities. This theme describes the process and point at which the parent takes responsibility and ownership for those choices, routines and plans that are and will be developed that will be unique to the needs of the parent, the family and the child with a significant disability.

In this study, this researcher found that those parents who reached out to other parents coping with their same situation found a new freedom to express both their fears for their own future with their child and their daily and long term concerns for their child. Parents became their own witness to the ambivalence of raising a child with a disability who had an unknown and, often, uncharted future. A mother (age 39) shared: "*My greatest fear is when the school bus doesn't show up anymore. I feel like the clock is ticking to the time when I will be alone with my daughter.*" A mother (age 34) and her husband (age 38) said: "*This is what it is and he is only going to get worse as he get[s] older. There are times when I'm changing his diaper that I get angry about it, like I just want this kid to go on the potty. I don't know whether to scream or to cry.*" Another mother (age 40) stated: "*There comes a point when you get tired of raising kids and it's not that I'm sick of raising my kids, it's just for the rest of my life I will be doing this.*" The parents in this study learned to accept that their child was who he/she was but when they considered the years ahead of hard work, pain, disgust, and disappointment they seemed to convey a sense of foreboding about their child's future.

Parents Restructure Their Identity

Kearney and Griffin (2001) describe the parental experience with a child who has significant disabilities as one that includes "joy and sorrow, an experience of paradox and ambiguity full of conflict and confusion" (p. 586). Todd and Jones (2005) reported that parents of children with significant disabilities felt they had lost their sense of self while caring for their child, and that their future expectations for personal development were still on hold. Marshak et al. (2009) discussed the process of personal reflection taken on by parents as "they must first respond to the news about the disability in their child and, second, confront their own beliefs about people who have disabilities" (p. 5). This researcher identified this theme from Boss's (2002) *Restructuring Identity* theme to identify some of the steps parents have taken in this study to become or maintain a separate identity from their child rather than becoming caught up in the role of constant caregiver or perpetual parent. Olshansky (1962) viewed this time in the life of the parents as "opportunities parents should take and be given [from society] to be away from their child at recurring intervals to get relief and enhance comfortableness" (p. 193). In the instance of a family with a child who has significant disabilities, the shift involves discovering ways to become more than a parent of a child with disabilities. For parents, it was essential to understand the idea that one's child is not broken but is different and they needed to learn to examine their own need to find connection with others outside the role of care giving. As one mother (age 51) said: *"Maybe it's not important that I make 100,000 dollars a year, but that I understand that my son is here for a reason and given to me for a reason to be a better person and to help others."* Another mother (age 70)

stated: *My son helped me; if not, we miss some corner we do not know. If you don't have a child you don't understand other mothers. You have an example to help others through."* In some ways, the theme *Parents Restructure their Identity* involves the parent's move into the next theme described below.

Discovering Hope in the Redefined Family

With the theme *Discovering Hope,* (Boss, 2006) described the goal in which parents were able to find ways to manage their lives with their now "normal" family that included a child with disabilities in such a way that the parent viewed the future in a more positive way and saw their child as having unique potential for growth and development. Olshansky (1962) proposed that this process would help parents achieve the goal of being comfortable with the reality that their child had a significant disability and accept their experience of chronic sorrow as a manageable chronic stressor (p. 193). It is very interesting that while every parent in this study did illustrate their increased comfort with their child's diagnosis, any positive views of their family situation were lost in the continued day to day struggles of living with a child who has a disability. A mother (age 40) shared: "*Right now I don't know, before I did. I would say within the last year, I felt like I had a purpose. I mean I know I have a purpose... um, but I feel like I have so much to offer. I want to be out there around people. I want to show the world my kids, but I feel like I am trapped at home now.*"

As a part of *Discovering Hope in the Redefined Family,* parents expressed a desire to avoid situations that produced any feelings of Chronic Sorrow such as family gatherings or sharing experiences with old friends. Instead, they chose to interact with

those people who understood and cared about their child; most had made the decision that the life they were living right then was the correct one as they parented their child with significant disabilities. A mother (age 30) stated: "*I just made my own friends and I found my own friends and I got my own people.*" Another mother (age 34) and husband (age 38) shared: *Cause when I am around the [old friends or family], I think, wow, he is way worse then I though he was. Like when you get around kids his age or way younger and they are doing a billion things. We think he is okay then we see other kids and we're like, oh crap, he is nowhere near these kids. You know like he really is messed up. But when he is here with us, we think it's normal with us.*"

One of the most notable statements made by these parents that illustrates their movement into *Discovering Hope in the Redefined Family* was the feeling that life with their child and all the challenges that that they had surmounted had made them stronger as it gave them purpose and direction. In addition, they noted that the ebb and flow of their chronic sorrow had become a familiar feeling. To say that their ebb and flow of chronic sorrow has been accepted would be incorrect; to say that it had become an expected part to their life would reveal a truer aspect of the experience. This is evident when a mother (age 54) shared: "*So when I was overwhelmed and still to this day when I'm overwhelmed I had to look and find what it is that will cause me to feel filled up again so that I am not sad by this and a victim. And, um, what I can do make me feel happy and at peace. So gosh that is a constant.*"

Ambivalence about the Future

The final theme, *Ambivalence about the Future*, was identified by this researcher to describe the uneasiness expressed by parents as they considered the future that lies ahead for their child after they are dead. They worried about who would provide the same level of care for their child that they had as parents -- a level of changeless support that few others would emulate. Although the parents involved in this study were at different points in their family life cycle, this worry and concern were shared by all parents at some point during their interview. It was noted that those parents with children who were below the age of early latency (chronologically) expressed a fear of what the future would mean for the parent when their child became much older. A mother (age 27) shared: "*Trying to figure out how I'm going to care for him as he continues to grow. When I start trying to think of that that is when it all becomes very overwhelming. If I take it a day at a time I can. I celebrate those achievements he has.*" For parents who were supposed to be in the stage of launching and moving into the generational stage of life, their concern was as much for themselves as older adults as it was a desire that their own child be cared for in a consistent and caring manner and be viewed as a person, aside from the disability. A mother (age 40) of two children with disabilities shared: "*Me leaving before them I think it is more of a reality now then it was then.... my oldest son is so fragile; he could never to into a home or anything like that. They don't do, I don't care what they say people like my oldest son who is phenomenal, they will treat him as a category.*" Clearly, these parents recognized that they were not launching their child but,

rather, they were dealing with a future in which their child might be left without a parent to care for them into the child's later years.

Marital Stressors

In addition to the themes, the parents in this study discussed their marital experiences in an open manner. Farber (1959) discovered in her research that marital relationships were more adversely affected in families who had boys rather than girls with a significant disability and that this negative affect was also associated with those families whose social status group was considered to be in the low rather than high or middle class range. The majority of the participants in this study were parents of boys except one; the responses from these parents when considering the gender of the child did not seem to differentiate concerning the difficulties that were experienced within the marital relationship. The difficulties identified seemed to relate more to the individual spouse's reaction to the diagnosis. Participants in this study shared the difficulties each experienced within the marital relationship as each spouse struggled with their own ability to make sense of the diagnosis given to their child. A mother (age 39) shared: "*We really had a hard time. So we almost split up and really didn't talk about her birth until 2 years after we were sitting in a lawyer's office thinking we had a case to go after the Doctor's. This was the first time I ever knew how he felt about the whole thing.*" Another mother (age 54) said: "*My husband, I think like typical males, 60% of all husbands leave because they can't deal with that, said, ya know I'm leaving at some point.*" A mother (age 51) said: "*My husband was not admitting that something was wrong with his first child. He said that I was the one who was crazy and that I was the one who was psycho*

analyzing everybody. Once our son was diagnosed, my husband pretty much went into his shell, didn't want to deal with the diagnosis. I left my husband twice. It was always me pushing him out or me leaving. When he came back I told him you either stay with me for the long run and know that your child has a disability and it's permanent." The youngest mother (27) in the group of participants described her feelings about marrying long after her son (age 7) had endured several surgeries and the adjustments she encountered in the process said: "*I married in 2007. Having a second parent is very difficult because I made all the decisions before. I have someone to argue with, my husband. He is very serious and looks at my son as his own. He is never embarrassed by him or to take him anywhere."* It is at these points that the individual responses to how the ebb and flow of chronic sorrow affects each family yields the realization that the role of a life- long caregiver can be a daunting concept that is not easily understood or processed by others who are not living in the same situation. The fear associated with a lack of true understanding as to who the child is now that a diagnosis has been received as well as what the diagnosis will mean for the family are all included in the experience of Chronic Sorrow. Individual spouses and the couples must consider what their personal beliefs are concerning people with disabilities as well as the beliefs of extended family and friends.

Ebb and Flow of Chronic Sorrow

As a concept, the ebb and flow of Chronic Sorrow was described by Olshansky (1962) as an experience that would wax and wane over the lifespan of the parent. It was found by this researcher that the parents in this study did indeed experience chronic

sorrow in greater degrees at the time of diagnosis and then at important milestones across the life of the family such as when the child's public school experience ended. The conclusion drawn by this researcher is that the prevalence of chronic sorrow became more pronounced for parents as they understood what the actual diagnosis would mean across their life span for both themselves and their children. This researcher found that the experience of Chronic Sorrow as a concept soon became an integral part of the emotional context of the family and that it remains under the surface throughout the life of the family. Chronic sorrow reoccurs when the child's disability leads to a narrowing of the parent's life expectations, decreased opportunities and connections for the child to individuals outside the world of disabilities, and the loss of resources and supports over the life span of the child.

To say that parents were consumed with their child's disability is, in essence, true as it is the disability that presents itself as the pivotal consideration in every thought, desire, plan or change contemplated by the family system. The interviews focused on the waves of chronic sorrow which moved in and out of the lives of all parents in this study as they repeatedly faced the loss of the expected child and lost dreams for the future life of the child. Parents expressed a deep chronic sorrow when they considered the lack of extended family involvement, the missed opportunities for their child to be involved in the normal activities that typical children enjoy, and the sense of aloneness found in the role of caring for a child with significant disabilities. The research conducted by Farber (1960b) which suggested that family support, community support and financial ability play a substantial role in the raising of a child with significant disabilities is still found to

be valid with this group of participants. The ebb and flow of Chronic Sorrow as a conceptual phenomenon is distinct in that its characteristics do not resemble grief or mourning; rather, these characteristics are experienced as an underlying sorrow that is present across the lifespan of the parent and child -- rising in intensity at developmental and transitional points that were anticipated or expected in the process of family maturation.

Chronic Sorrow as a Chronic Stressor

Chronic Sorrow may be considered a Chronic Stressor as described earlier by Olshansky (1962) and by Boss (2002) in her Contextual Model of Family Stress as "one that disturbs the equilibrium of the family system over a long period of time" (p. 54). As concepts, both Chronic Sorrow and Ambiguous Loss (Boss, 2006) describe a relational problem between two or more individuals, in this case a parent and child, that exists across the family lifespan long after the diagnosis is received. From this research, three key issues can be linked to a permanent, life- long shift in the relationship for the parent as he or she moves from being a parent to being a joint parent/caregiver: the level and quality of the child's verbal communication; challenges for the parent resulting from the child's behavioral issues such as toileting; and, continued medical interventions to resolve difficulties linked to the child's disability. For example, parents may experience unresolved chronic sorrow when they must continuously adapt or increase skills such as communication skills that help them focus and learn how to read and understand what the child's needs are either through non-verbal gestures, limited sign language or simple verbal communication. One mother (54) described the emotions associated with the day

that her son spoke his first word at 6 years of age; she like many of the other parents involved in this study voiced the feelings of excitement over the newly developed skill as well as the feelings of sorrow associated with the delayed conquering of this milestone.

For many of the parents in this study, they learned quickly which friends or relatives would be able to "stay the course" and provide care for their child. One of the older mothers (70 years) had worked to establish a network among her extended family such that several family members lived in her home for the purpose of providing care for her until he reached the age of 15. At that point, she realized that she and her husband needed to find a network of trusted friends to build a circle of safety for their son. When the time arrived to consider who would provide care and support she determined that she would leave guardianship of her (now) 35 year old son after her death to a friend rather than to a relative. The longing for extended family to become involved and acquainted with the child who has significant disabilities adds to the experience of chronic sorrow for these parents. Many participants reported a feeling of rejection by extended family as those individuals chose to remain uninvolved or unwilling to establish a relationship with the child choosing to keep the relationship on the edge of disconnection.

Expanding Theories to Include Chronic Sorrow

Family Life Cycle Theory

These case studies looked at the experience of seven sets of parents who were selected to illustrate several Family Life Cycles stages: (1) the family with young children, (2) the family with adolescents, (3) launching children and moving on, and, lastly, (4) the family in later life (Carter and McGoldrick, 1988, p. 17). Family Life

Cycle looks at three primary aspects of family development: predictable changes, transitional patterns in the life cycle, and the role of therapy in assisting families through difficulties with these transitions (p. 4). Predictable changes as defined by the Family Life Cycle theory are those identified specifically for each of the family stages based on the needs of the children. The family with young children are focused on the acceptance of new family members into the system (Carter et al., 1988, p. 17) and learning to be parents; the family with adolescents are experiencing the development of autonomy in the relationship between parent and child; the family launching children are experiencing the movement of their child toward independent living and the subsequent end to the parental role as filled in previous stages. Families in the later life stage are entering the stage of life without children as the main function or role as parents pursue individual interests and experience losses associated with the death of a spouse, health and the aging issues.

This researcher looked at how the predictable changes expected within each stage of the family life cycle was experienced in a very different way by the parents whose child is diagnosed with a significant disability. As stated above, these predictable changes are tied by Carter and others (1988) to coincide with the expected developmental growth of the child and the life cycle transitions of the individuals and family. The families who were caring for their child with a significant disability did not experience those predictable developmental changes that would have marked when the child rode a bicycle or attended a prom (Patrick-Ott & Ladd, 2010). Rather, it was the lack of those expected changes that led this researcher to conclude that parents continued to experience an ebb and flow of sorrow (chronic sorrow) as they realized that there was almost a

universal lack of meaningful developmental change over time for their children diagnosed with a significant disability. As a matter of fact, many parents in the third stage listed below actually reported that their child lost skills once they "graduated" from high school at age 22 when the child experienced a dramatic loss of services and activities designed to promote continued skill-building. There is a need for a separate series of stages for children with significant disabilities.

The focus of the suggested adaptations below includes the family system, the parent as an individual, and the child with the disability. This researcher proposes that the following adaptations to the Family Life Cycle Stage Theory (Carter and McGoldrick, 1988) be used when professionals work with children diagnosed with significant disabilities:

1. The Family, Parent, and Child at the Time of Diagnosis
2. The Family, Parent, Child, and Disability through the School Years
3. The Family, Parent, Child, and Disability after Launching Back into the Home
4. The Family, Parent, Child, and Disability in Later Life.

The family, parent, and child at the time of diagnosis. This researcher believes that the transition to a life that will include full time care-giving is a life cycle stage that is unique to this family system. Parents encounter this stage at the time when they begin to search for answers to questions regarding slowed development, behavioral discrepancies, or in response to the concerns of other individuals who are in their lives that may have voiced questions about differences they have noticed but the parent may have discounted. Questions from parents are multiple in this stage due to their new role

as a parent and their fear of being judged as a parent who lacks knowledge in the areas of normal development. The search to locate professionals who possess an expertise in the areas of developmental disabilities becomes paramount as the parent's desire to gather information for the questions about their child increases. The focus during this stage is on the disability diagnosis, the care and attendance to the needs of the child, and the parent's desire to locate information that explains what their child's diagnosis will mean for the parent, the child, and the family. Once a diagnosis is received, which usually takes a considerable amount of time and numerous visits to medical professionals, parents move into the process of information gathering to increase both their understanding and acceptance of their child's specific diagnosis. Not only does the diagnosis bring an added component of consideration as to how it will change their family system but parents are also engaged in an intrinsic process of personal exploration about what it may mean to be the parent of a child with a significant disability or multiple disabilities.

The family, parent, child, and disability through the school years. For parents whose children are in school, their duties include the organizing, planning, and implementing those activities that concern the day to day activities and responsibilities for every member of the family. The parents in this study emphasized that the particular and, often, very sensitive needs of their child with a significant disability became the focal point for all family plans. Nearly all parents indicated that the siblings of the child with significant disabilities were supportive, helpful, and even, protective of their siblings

– but these siblings were also quite normal in that they wanted their own moment to be special and the center of attention.

The primary importance of this stage is to maintain a routine in the life of the family that creates and supports a feeling of normalcy. Most parents in this study noted that unexpected changes in school services or health of the child challenged the parents to be creative and adaptive as the changes created difficulties for family members. For example, the parents of a child who is 12 or 13 and is developing in a "normal" way can assume that the child can take care of him or herself for several hours if left alone. For the parent of a child with multiple disabilities, leaving the child alone for any length of time still necessitates the need to be able to hear the child and be able to respond quickly as the child may be unable to care or protect themselves. In another example, the husband and wife in this study worked diligently to find a time to take a vacation together and found it when they identified a week-long camp for their child. That same couple struggled with the decision to have another child as they did not know how their marriage would survive the birth of another child with significant disabilities.

Making sure that all of their children were involved in after school care and summer activities was a challenge for parents when both worked outside the home, but especially when they had to be sure that the vehicle transporting their child was large enough for the wheelchair or other equipment needed by the child. Changes in work schedules or even leaving a full time position to provide care for the child with significant disabilities was a common occurrence for the families in this study as they found the cost of providing services and resources to fill the gaps in school services can

be difficult to locate and too expensive to pay for. Most but not all parents in this study were adequately informed about all available State programs and funds available for their child.

The school years are often thought of as a time of respite (Marshak, Seligman, & Prezant, 1999) for parents, as it is during this point that parent experience the resemblance of a the normal process of maturation in the family life cycle. The parental care giving duties are shared with others in the school system during a specific block of time during the day, thus allowing the parents to pursue activities outside the home which may include volunteering, developing support groups, pursuing college education or perhaps part-time employment as noted in the study participants. All school activities are valued by parents of children of any ability or disability, but for the parents of a child diagnosed with significant disabilities, the respite that school provides is invaluable to the parents' need for time away from the dependency of their child and their significant needs.

The family, parent, child, and disability after launching back into the home. This stage of "laughing back into the home" provides a dramatic example of how the experience of parenting a child with significant disabilities is different from that of a parent of a "normal" child. About the time the "normal" child reaches the age of 18, the majority of parents correctly expect that their child will complete high school and begin the move or launch out of the home into full independence by going to college or working full time. For families that have children with significant disabilities this process is reversed: the child is launched back into the home to live a dependent life --

full time. For this adolescent or young adult child with significant disabilities, the stimulation offered through school attendance and interaction with others outside the immediate (often until age 22) ends and the child enters a time of isolation with the possible feeling of being abandoned by their teacher or even of being trapped in their home.

For the parents in this study who chose to keep their child at home in a loving environment, a new struggle emerged – to petition the appropriate stage agency for continued and, perhaps, enriched benefits for their child. More than likely, without parental advocacy for their child, the now adult child could slip into a daily routine in which they had little contact with others and even less stimulation and social interaction within their community in which they live. For the parents, the appearance of their child, now a grown adult, who is in many respects still the same cognitively, socially and emotionally as they were the day the diagnosis was given is again part of the ebb and flow of Chronic Sorrow.

The family, parent, and child with a disability in later life. Over time, parents will continue to parent their child no matter the level of dependence, but a shift occurs as the parent now faces the reality that this responsibility and the accompanying chronic sorrow will end only at the death of the parent or the child. The bond to the child strengthens over the years of caregiving, and at the same time so does the concern for the child's care if and when the parents become ill or dies. Farber (1959, 1960a) stated that the disability in a child would have an adverse effect on the adjustment of the typically developing brother and sisters in their family roles and the disability of the child would

prevent this family system from moving in a forward motion of family life. It was believed by Farber that the disability would in effect "disable" the other family members from moving past the launching stage and place the family in a holding pattern. When considering the stories related to this researcher by the participants in this study, movement through the family life cycle was evident, although at a differing level of maturation. Those parents who families included typically developing siblings expressed the admiration for the maturity and compassion demonstrated by the siblings of the child with significant disabilities. The launching of the child with significant disabilities was not considered to be of paramount significance to the maturation of the family by Farber and her colleagues. Parents in the study expressed the need to provide a sense of well-being, safety and happiness for their child with significant disabilities as one of primary importance, deferring the consideration of future plans was not due to denial or fear but one of intense contemplation toward the final decision of who would be the designated guardian for their child as being one that they could be comfortable with rather than one that left them feeling they were without a choice due to uncontrollable circumstances.

Parents involved in this study voiced the concern about locating a substitute caregiver in the event of their absence as one of paramount importance as they moved into this stage of the family life cycle. Parents expressed their concern about finding an individual who would provide the "right fit" for their child both in terms of that individual understanding their child's diagnosis and understanding their child as an individual outside the diagnosis of the disability. Parents noted that they wanted the person who would assume responsibility for their child to view their role as more than

simply providing care for them. They were aware that they would not find another caregiver who would duplicate what they as the parents had provided for their child, but believed if they are able to locate a person who was able to develop a meaningful relationship with their child, the caregiver duties would not seem to be just a job. The parent-child relationship that had developed over the course of their lives for the parents in this study included a deep connection that transcended the emotional element alone, it required the parent to step outside the parental role and move into the role of advocate, interviewer and, ultimately, employer as they sought to locate an individual, group home or agency that would meet their child's needs. Parents in this study provided a significant level of detail concerning the depth to their experience as both a caregiver and parent to their child and to the deep sense of responsibility they felt while fulfilling the demands of both positions. Now in this final stage of the family life cycle, the parent must anticipate an end to their own parental/caregiver role and make the best plans that they can for the uncertain future of the child they will leave behind; they plans call for their identification of a replacement for themselves and the belief that they have made the right decision for their child with significant disabilities. The expansion of the four family life cycle stages to include families with a child that has a significant disability is necessary for both the families and professionals.

These modified stages of the Family Life Cycle Theory (Carter and McGoldrick, 1988) provide a more accurate understanding of the unique experiences found in families who have children with significant disabilities. It is strongly urged by this researcher that the disability be included in the stages of development for the family since it is the

disability that is the unpredictable agent of change and transition within the system as well as the culture and interactions within and outside the family. As seen from the descriptions, the changelessness of the independence of the child becomes more evident as the years pass and milestones of full independence are never achieved.

Contextual Model of Family Stress Theory

Boss's (2002) description of family stress in the Contextual Model includes the meaning of stress from a cultural perspective, the current developmental level of the family, and constitutional make-up of the individuals in the family. Boss (2002) expanded Family Stress Theory past the linear ideas of the causes and effects of stress on the family into a focused investigation of the resilient strengths families use to meet the needs of the stressor (p. 28). In the Contextual Model of Family Stress (Boss, 2002) suggests that the notion of Ambiguous Loss can be explained as a dichotomy in how each family member perceives the meaning of the stressor as either a psychological or physical loss. Their perception of the stressor influences how each member in the family responds to the stressor both internally and externally, and, finally, how the outcome is related to the perception of the boundary ambiguity.

Boss (2002) defined ambiguous stressors as occurring in situations that can persist over long periods of time and persisting even when evidence of the stressor may not be truly understood to outsiders or even to extended family (p. 55). Boss (2002, p. 57) describes ambiguous loss as a structural problem which leads to boundary ambiguity; the ambiguity of the stressor lies in the individual's inability to obtain the needed facts about an event or situation that can facilitate a closure or ending. This lack of closure

perpetuates boundary ambiguity as the family is unable to move forward and do their necessary work such as reassign family roles or develop new rituals in the face of so many unknowns. Within Contextual Family Stress Theory, the concept of Ambiguous Loss is described as an "an incomplete and uncertain loss" (p. 3) that occurs in two different ways: the family member can be physically present but psychologically absent, or physically absent and psychologically present. Families must strive to resolve their experience of ambiguous loss, or else the losses could very likely control ordinary events as well as shape the long term experience of every member of the family (Patrick-Ott & Ladd, 2010). Solnit et al. (1961) describe the experience of loss as "the ghost of the desired expected healthy child." (p. 532). Boss (2006) claimed that the experience of ambiguous loss is the "most stressful kind of loss because it defies resolutions and creates long-term confusion about who is in or out of a particular couple or family" (p. xvii). It is this level of stress created by the ambiguous loss that can affect the "path a family follows as it adapts and prospers…both in the present and over time" (Hawley & DeHaan, 1996, p. 293). Boss (1999) theorized, "internal shifts are often linked to external control" (p. 109).

This researcher used several of the therapeutic goals described by Boss (2006) within the construct of Ambiguous Loss to expand Olshansky's notion of Chronic Sorrow as a chronic internal stressor. It is the hope of this researcher that such an expansion of the model will enable further applicability of the Family Stress Theory to families who have children with significant disabilities; it is possible that the concept of Chronic Sorrow is a special case within the Contextual Model of Family Stress. The therapeutic

goals outlined by Boss (2006) in relation to Ambiguous Loss and Boundary Ambiguity were found to be applicable to the research themes identified by this researcher from the interview transcripts of this study. This study worked toward the expanded use of the Contextual Model of Family Stress, Ambiguous Loss, the Family Life Cycle Theory and the concept of Chronic Sorrow to help family scientists understand and accept the parental reaction and subsequent changes that occur within the individual, parent, family, siblings and marital relationships as each of these systems adapts to meet the needs of the experience which includes a child with significant/multiple disabilities.

Family Systems Illness Model

As reported by parents who participated in the study, the realization that their child's life-long disability was not going away, that their care-giver role would be lifelong, and the dependence of their child would extend across the life span of the parent illustrates the centripetal period which is described by Rolland (1994) as an underlying component to this family system. In this researcher's opinion, Rolland's centripetal period corresponds to two themes identified in this study: the *Initial Chronic Sorrow Reaction to the Diagnosis* and *Finding Meaning in an Overwhelming Situation.* At points during the interviews with parents, this researcher noticed that parents focused on internal family issues right after receiving their child's diagnosis in an effort to understand the disability. Parents began to immediately search for community and medical services that would increase the developmental opportunities for their children and to modify both their own ambitions and family routines for an undetermined amount of time. While the stress experienced during the centripetal period can lead to family difficulties, the

families in this study chose to reframe these difficulties in terms of skills they had developed over time to deal with their continued need to focus on the internal workings of their family and the real possibility that their child diagnosed with significant disabilities would not grow up and move away from home. In the centripetal period and across the two themes identified above, the family grows to understand and find meaning in their unique situation of having a child continuously dependent on the parents and the family.

In the themes described as *Normalizing the Ambivalence of Parenting* and *Discovering Hope*, this researcher found parents making efforts to move toward an outward focus which is described by Rolland (1994) as a centrifugal period. This move was accomplished (partially) when state policy towards children with significant disability mandated that the child be allowed to attend school until the child was 22 years old. In the 9-month period that the child was in school, the parent had a measure of time to work outside the home, attend classes, and/or provide care for younger children; for a brief time, parents could act separately from their child's chronic level of dependence and the constant realization that they are and will continue to be the parent of a child with a significant disability. Curiously, the parents in this study did not express bitterness or anger at the constancy of their parenting responsibilities; rather, they appeared to have found their own meaning in their situation as they determined to provide the best possible care for their child and the other members of the family – even when difficulties could not be avoided. For the families in this study, it is apparent that their movement between centripetal and centrifugal was based on the unique needs of their child with a significant

disability. If the child required additional medical care, experienced difficulties with school services, the outside focus was enhanced and adaptations of the parents to the child and the disability were resolved as quickly as possible.

Understanding the chronicity of being a lifelong care-giver is an experience that was continually being processed by the parents in this study as they moved across the lifespan with their child. Each participant, no matter what was the chronological age of the child, continued to mention the realization that they would be doing this for the rest of their lives. It is believed by this researcher that this interview process provided parents with an opportunity to share their story of being the primary caregiver for a significantly dependent child even after as many as 30 years. One participant had stated that she was tired, but determined to continue to raise her two children who were both diagnosed with disabilities, even though she had thought that at some point she would have been finished. Talking with the researcher seemed to allow this mother, a long-term caregiver, a brief respite from the overwhelming finality of her role. By having the opportunity to share this information with this researcher, the parents in this study were able to validate the fact that they had provided a significant level of care for their children diagnosed with significant disabilities. Voicing their successes and concerns with another person who appeared to understand or who had connected to the family can provide important relief for parents and lead to a renewal of strength.

Experiential Family Therapy Theory

Neill and Kniskern (1982) discussed the Experiential Family Therapy Model as proposed by Carl Whitaker in which healthy family development is enhanced when there

is "flexibility in the assignment of the necessary roles to its members" (p. 18). He also suggested that as a family moves through biologically determined time spans that the family members would experience a "dynamic tension between the needs of individual members for individuation and the needs of the family system" (p.18). It is at these points or transitions of obtaining a diagnosis, learning about the disability and their child, understanding the role and job of care giving in addition to parenting, and the ultimate realization that the ending to such roles and assignments are accomplished only through the death of the parent or the child are the experiences that shape the behaviors of parents and are a part of the ebb and flow of chronic sorrow. These dynamic tensions were evidenced through the statements and struggles given by participants in this study as the internal journey of learning to be a parent of a child with a significant disability across multiple years.

Whitaker (1989) explained that the "challenge we all struggle with endlessly is that most of us live a fragmented life; we are either preoccupied with the horrors or the glories of the past or we are preoccupied with the horrors and glories of the future "(p. 52). Whitaker proposed that we are human beings and not human doings and it is at that point when we realize this concept we have begun to learn to live in the present and move to live and grow from the experience of that moment. He understood the art to living to include the development of personhood and becoming all that you can be by allowing the emotional context of the experience to flow. This researcher suggests that Whitaker's description of growth, change and development of personhood is being practiced daily by families who have children with significant disabilities. This practice involves learning

to develop their own personhood as parents, the personhood of their child, experiencing the rawness of vulnerability and rejection by those who are family, and at the same time locating the strength to move ahead and accept the challenges on the horizon. It is these struggles of humanness that would be valued in the model of Experiential Family Therapy. The experience of Chronic Sorrow is a normal response to a tragic fact, and it does cause parents to walk a path that is unique and personal.

Limitations

This research study included a sample size of eight families and is only a small window into the life of parents who have children with significant disabilities. The study was geographically limited to North Texas area which limits it applicability to the larger population of families who live in the United States. The amount of families with children with significant disabilities had a higher percentage of males compared to females and also provided the input from only one father in the interview process. Time limitations for the study also played a large role in the ability to gather perspectives from parents of different races and varying social economic status'

Recommendations

Further research considerations may include conducting a study with a much larger sample size to include more input from different races. A study that concentrates solely on interviews with fathers of children with significant disabilities could open the research knowledge base to another side of the parenting experience. Investigating the experiences of parents with daughters in comparison to sons would also provide a greater opportunity to understand the differing expectations parents may have in accordance with

the roles that culture may play when the disability prevents the child from fulfilling the expected role of a son carrying on the family name, or the daughter being able to provide grandchildren. Developing a study that would be able to solicit interviews from a nationally representative sample would lend to the applicability of the conclusion proposed from this research study.

Educational workshops and training to medical professionals, mental health and behavioral health communities is needed to provide insight and knowledge regarding the struggles and experiences of parents who are parenting children with significant disabilities is needed. This research study indicates that long-term follow up by both medical and behavioral health professionals is needed by parents from the professionals who provided their child's diagnosis. While the eight families in this current study were functioning in a healthy way, they would have benefitted from receiving care from a better educated and supportive behavioral health community. Professionals from both the medical and behavioral health communities are encouraged to continue to dialogue with families with children having significant disabilities on updated diagnostic criteria and treatment options and the continued adaptation of the family to the needs of the child as the child grows into adulthood. This researcher also suggests a familiarity with the particular diagnosis of the child to help with questions that may arise during interactions with the family and to provide relevant information to help answer the questions. Professionals should be aware that parents may reject the standard informational brochures and pamphlets that describe their child's disability in a standard fashion, and may look to the professional to provide them with the real life scenarios involved with a

significant disability diagnosis. Understanding the effect that a long term diagnosis of significant disability may not be fully understood until later in the process of parenting is of great importance to families. The professionals involved with parents are encouraged to take an educator stance in their interactions to allow opportunities for information gathering that is geared toward the need of the families and the significant disabilities of the child.

Additional studies that focus on the experience of the child with significant disabilities launching back into the home after school services have been aged out of is also needed to further assist professionals in understanding this process and the subsequent needs that arise during this point in the family life cycle. Research that focuses on the resources currently available to families who have children with significant disabilities is also needed to identify resources that are needed by this specific populations could reveal needed legislative changes to be initiated by local, state and federal programs currently given to families. Particular attention in this area should be given to the change in needs of families whose child has launched back into the home and the ancillary supports and services currently available. Research regarding the available opportunities to provide community interaction of the child with significant disabilities after school services have been exhausted is needed. Parents in this study voiced the concern regarding how their lives will change again once the structure routine of school is no longer available. Individuals with significant disabilities loose interaction with their local communities when the avenues of interaction rely solely on the parents or guardians who are filling the role of fulltime caregiver.

Another recommendation of this study is to increase the base of information about the long-term experiences of families with a child diagnosed with a significant disability. While the sample may be unique because it was self-selected, the information provided by the parents illustrated the experience of parents who chose to fight for their children and did not stop until they had the best possible medical diagnosis and continued to be educated on the long-term developmental challenges ahead for their child. Parents of children with significant disabilities need to know about the satisfaction and love that parents receive in parenting their children.

Finally, family therapists are encouraged to become familiar with this unique population and the continued struggles that are experienced, especially the existence of chronic sorrow and its relation to the difficulties experience in the marital relationship related to the stress, fear, and possible rejection by extended family when a child has a significant disability. Providing family therapy to this family system that experiences change in a distinct way provides an opportunity to enhance therapy practices to include marriage counseling that is structured specifically to include the experience of living with a child who has a significant disability and the challenges associated with this experience.

Conclusions

This study investigated the concept of Chronic Sorrow and its existence within seven families of children with significant disabilities. The parents in this study shared those deep emotional responses that Olshansky (1962) described as Chronic Sorrow that parents have continued to experience in ebbs and flows across their lifespan and the development of their child. This research brought to light the ongoing work begun by

each parent from the moment their child was born through the medical diagnosis of their child and, then, as parents they began their struggle to understand and know their child on a daily basis across time. This research provided a broader view of the experience of parents with a child diagnosed with a significant disability as parents expanded their personal loss of embedded expectations for a "normal or typical" child to include their realizations that their child may not be accepted by extended family or society. Through qualitative interviews, parents shared how they came to realize that their parenting and care-giving would stretch across their own lifespan and that the disabling condition their child experienced would change over time and that the vulnerability of their child would extend, very likely, beyond the lifetime of the parent. Dealing with the future security of their child was of key importance to the parents in this study.

The ebb and flow of Chronic Sorrow was found to be linked to the changelessness of the parenting role through interviews of parents in this qualitative study. Small developmental triumphs made by the child brought parents joy and celebration, but also served as a reminder that the child would not reach full independence at adulthood and would remain dependent upon others to provide their much needed care and protection. The interviews revealed how the initial reaction to the diagnosis continues across the life span of the parent as new losses and understandings of the significant disability unfold for their child. This research study found that parents work hard to create a 'normal' routine around an ambiguous loss and that the response of being focused on the child and the disability is in fact a normal process within this family system. Learning that a child has a significant disability involves more than one visit to the doctor for the diagnosis.

Emotions that are experienced over the news of a disability last longer than a few moments after reading or hearing what the results of tests have found. Struggles to make sense of the world that now involves a child with significant disabilities includes understanding the disability and the fact that it is now a part of the family and the decision making processes that occur throughout the lifespan.

Chronic Sorrow is not a pathological response to learning of a disability, and the parents in this study did not work to deny the presence of the condition of their child. Chronic Sorrow is continual as it moves like waves over a sandy shore such that with each newly understood dimension of the child's significant disability and its meaning for the parent's lifelong care-giving role brings a new tide of chronic sorrow. The intensity of the sorrow varies from experience to experience as parents begin to recognize that chronic sorrow is, once again, moving in their lives. This study has provided an avenue to increase our understanding about the personal lives of parents who have children with significant disabilities.

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APPENDIX A
CONSENT TO PARTICIPATE

TEXAS WOMAN'S UNIVERSITY
CONSENT TO PARTICIPATE IN RESEARCH

Title: The Experience of Chronic Sorrow in Parents Who Have a Child Diagnosed With A Significant Disability: Investigating Chronic Sorrow Across Parental Life

Investigator: Amy Sue Patrick-Ott.....amysuepatrickott@msn.com/940-368-7176

Advisor: Linda Ladd, PhD.....lladd@mail.twu.edu/940-898-2684

Explanation and Purpose of the Research

You are being asked to participate in a research study for Ms. Patrick-Ott's dissertation at Texas Woman's University. Chronic Sorrow has been defined a prevailing feeling or sense of loss when considering the expectations and demands associated with parenting a child who has been diagnosed with a significant disability. The purpose of this study is to determine if Chronic Sorrow is a phenomenon that is experienced throughout parental life of parents who have a child with significant disabilities; it will also investigate what events or milestones facilitate the Chronic Sorrow phenomenon.

Research Procedures

As a participant in this study, you will be asked to engage in a face to face audiotaped interview with the researcher. A time commitment of 3 hours can be expected to complete the study. The first face to face interview will be 2 hours. The final interview will be 1 hour which will consist of a review of the interview content gathered from the first interview to enlist accuracy of the data collected from the research participant. Should you become tired or upset you may take breaks as needed. You may also stop answering questions as any time and end the interview without penalty. The interview will be scheduled at a time and place that is convenient for you as the research participant. The interview can be conducted at your home or in a neutral setting such a library.

Potential Risks

There is a potential risk of loss of confidentiality with any email, downloading, and internet transactions.

Participants may experience discomfort due to the interview material. A list of mental health service providers will be provided for your own personal use should you need to speak with someone about the subject matter presented in the study.

Initial

This study will include topics that may be of a sensitive nature. Participants will be encouraged to take breaks or stop the study at any time

The researchers will try to prevent any problem that could happen because of this research. You should let the researchers know at once if there is a problem and they will help you. However, TWU does not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.

Participation

Your involvement in this study is completely voluntary and you may withdraw from the study at any time. Your participation in the study will not be compensated in anyway.

Questions Regarding the Study

You will be given a copy of this signed and dated consent form to keep. If have any questions about the research study you should ask the researcher; their phone numbers are at the top of this form. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the Texas Woman's University Office of Research and Sponsored Programs at 940-898-3378 or via email at IRB@twu.edu.

1) If you would like to know the results of the study, please provide a mailing address in order to have the information mailed to you:

_____
Signature of Participant

_____
Mailing Address

_____
City State Zip

_____
Printed Name of Participant

_____
Date

APPENDIX B
WEBSITE POSTING

Are you a parent of a child who has been diagnosed with a significant disability? Does your child's disability hinder his or her ability to live independently? Are you the primary caregiver that is faced with making major life decisions for your child? Will your child need a care giver throughout their life?

Amy Sue Patrick-Ott, LPC, a doctoral candidate in the Family Therapy Program at Texas Woman's University is conducting face to face interviews with parents fitting this description who wish to volunteer for this study. The study will be looking at the concept of Chronic Sorrow. Chronic Sorrow has been defined as a prevailing feeling or sense of loss when considering the expectations and demands associated with parenting a child who has been diagnosed with a significant disability. The study will include two interviews: the first interview can be conducted with participants at their home or at another location such as a library and will be audio-taped and will be 2 hours in length. The final interview will be 1 hour and will allow participants to review the data collected from the first interview. The research will focus on the life- long experiences the parent has had while parenting a child diagnosed with significant disabilities. Questions will focus on feelings, emotions, loss and dreams or expectations associated with this process.

If you are interested in the study of the experience of chronic sorrow in parents who have a child diagnosed with a significant disability, please email your contact information to amysuepatrickott@msn.com. The primary investigator, Amy Sue Patrick-Ott, LPC will contact you to set up a date and time that is convenient to conduct the face to face interview.

There is a potential risk of loss of confidentiality with any email, downloading, and internet transactions. Participants may experience discomfort due to the interview material. A list of mental health service providers will be provided for your own personal use should you need to speak with someone about the subject matter presented in the study. This study will include topics that may be of a sensitive nature. Participants will be encouraged to take breaks or stop the study at any time

APPENDIX C
SCRIPT

Script

Thank you for agreeing to participate in my research study, *The Experience of Chronic Sorrow in Parents Who Have a child Diagnosed with A Significant Disability: Investigating Chronic Sorrow Across Parental Life.*

This research study will include parents who are considered to be one of the four categories of the life cycle (Parents of Young Children; Parents of Adolescents; Parent who are Launching Children and Moving on; Parents in Later Life) and are parenting a child diagnosed with a significant disability. Your participating will assist the researcher in understanding the experience of chronic sorrow and the possible link to the significant disability diagnosis of their child. The study will look at the development of the child with the significant disability in relation to the development of their independence and the development of the parent from their parental role. We will discuss growth and development in families; specifically the expectations for the development of independence in children and how these delayed or unmet expectations may influence expected changes in the family roles to be slowed. This study will investigate the ways parents experience these delayed developments and the possible existence of chronic sorrow associated with these experiences.

Since communication between you and the researcher may involve emailing, downloading and internet transactions, there is a potential risk for a loss of confidentiality. Participants may experience discomfort due to the interview material. A list of mental health service providers will be provided for you own personal use should

you need to speak with someone about the subject matter present in the study. This study will include topics that may be of a sensitive nature. Participants will be encouraged to take breaks or stop the study at any time. Thank you again for volunteering to participate in my research.

Amy Sue Patrick-Ott M. S. LPC
Doctoral Candidate for Family Therapy
Texas Woman's University
Denton, TX

APPENDIX D
LETTER OF AGREEMENT

April 22, 2010

Amy Sue Patrick-Ott MS LPCI
PO Box 40
Gainesville, TX 76241

Dear Ms. Patrick-Ott

Partners Resource Network has agreed to allow Amy Sue Patrick-Ott, a doctoral candidate in the Family Therapy Program at Texas Woman's University to post information regarding her research project to obtain interested participants in her study on the PRN Website (www.partnerstx.org).

Partners Resource Network understands that it will not have control over the study, nor will access to the data be made available for PRN's private use.

The information regarding the research study for Ms. Patrick-Ott's dissertation project will be used only for the dissertation research project titled: *The Experience of Chronic Sorrow in Parents Who Have a Child Diagnosed With A Significant Disability: Investigating Chronic Sorrow Across Parental Life.*

Sincerely,

Janice Meyer
Executive Director
Partner's Resource Network
1090 Longfellow Drive Suite B
Beaumont, TX 77706

APPENDIX E
RESEARCH QUESTION AND CENTRAL PROMPTS

RESEARCH QUESTION FOR SEMI STRUCTURE INTERVIEWS

What is the long term experience of adult parents who have a child diagnosed with a significant disability, when the concept of Chronic Sorrow is the primary focus of this case study research?

Central Prompts

The following prompts will be used to guide rather than direct the interviews:

1. Parental reaction to the medical diagnoses of their child.
2. Parental experience of the loss or delay of their child's developmental milestones.
3. Parental experience of raising children who have a significant disability alongside children without special needs.
4. Parental experience of marriage or being single while raising a child with a significant disability.
5. Parental experience of support from extended family.
6. Parental sense of loss of self over time.
7. Parental reaction to the changelessness of their role as parental caregiver.
8. Parent's ability to discuss their child's future after the parent's death.

APPENDIX F
DEMOGRAPHIC QUESTIONNAIRE

Demographic Questions

1. What is your race:
    a. White
    b. Black or African American
    c. Hispanic or Latino
    d. American Indian and Alaska Native
    e. Asian
    f. Native Hawaiian and Other Pacific Islander
    g. Some other race

2. What is your gender
    a. Male
    b. Female

3. What is your relationship status
    a. Married
    b. Divorced
    c. Separated
    d. Cohabitating
    e. Widow

4. How old is your child who has significant disabilities?

5. How old were you when you were told about the disability?

6. Do you have other children living in the home?

7. How old are your other children?

8. How old was your child with significant disabilities when they were first diagnosed?

9. What birth order is the child who is diagnosed with significant/multiple disabilities

10. Does your child with significant/multiple disabilities attend school?

APPENDIX G
COUNSELING RESOURCES

Texas Department of Aging and Disability Agencies

MHMR Services of Texoma
315 W. McClain
Sherman, TX 75090
877-227-2226 Crisis Line
www.texomamhmr.org

MHMR Service of Tarrant County
1300 Circle Drive
Fort Worth, TX
76119
817-569-4100
www.mhmrtc.org

Dallas Metro Care
1380 River Bend Drive
Dallas, TX 75247
Tel: (214) 743-1200
Toll Free: (877) 283-2121
Fax: (214) 630-3469
Website:
www.metrocareservices.org

Therapy and Counseling Services

Positive Outlook Counseling
1912 E. Hebron Parkway
Suite #104
Carrollton, TX 75007
(214) 629-9491

A Better Tomorrow Counseling
110 E Pecan St
Gainesville, TX 76240
(940) 665-8056

Erin Humpheries LMFT LPC
13101 Preston Road Suite 504
Dallas, TX 75247
817-703-8768

APPENDIX H
INTERVIEW TRANSCRIPTS

Cathy (34) and David (38), parents of a 31/2 year old son diagnosed with Fragile X Syndrome report:

"Our pediatrician wanted to take a wait and see approach; we just wanted her to do more. We had him a year and nine months before a diagnosis.
I was waiting on something I just didn't know what. There was probably more of mental shock going on just trying to comprehend the news. Wow… he is way worse than I thought, you know like he is really messed up. It was devastating. We didn't expect a like a lifelong disability."

"I read everything. We work around it as best as we can. These are the cards I have been dealt. I think it helped bring us closer, we work harder to not let our marriage fail. It's given us a purpose in our marriage. I try to focus on what I can with him now. My main goal, the most satisfying of being his parent, seeing him mostly happy, I think it is what you do with it, the sorrow and how much you turn it into something positive for yourself and your kid."

"It's not as bad as you think. You're going to go from this joyous level up here you know 180 degrees to complete nothing down here. You're still going to love the kid and have many moments of joyous celebrations. It is a struggle but it is worth it. You have moments when you go oh my God he'll never do this or that, they just come over you. You are always looking at your kid and saying to yourself there are some things this kid will never achieve."

"I think it has made us stronger. I think it has helped bring us closer. It's a better vehicle for communication, we are a unified front. We wanted him to be normal or be able to function in society. It is hard for us at a social perspective. Talking about it makes it more real. I don't like to think about it very often"

"What is his future? He won't go to college and experience things. This is what it is and he is only going to get worse as he get older. There are times when I'm changing his diaper that I get angry about it, like I just want this kid to go on the potty. I don't know whether to scream or to cry. It is sad not to know, it is sad for him because he can't tell me so I can fix one problem and it is sad for me cause I'm standing here completely pissed off at this kid who is completely innocent."

"It's hard to be around people who don't have kids with special needs. I can't sit with my girlfriend who has a 3 year old who is writing his name and doing things when my kid can't say his name or momma for that matter. It's a struggle but it is

worth it in a nutshell. It was a rough first year but it gets better. I can only think about today but not 10 years ahead. I never think about that. Yeah it's day by day, just living day by day."

"My sister said he's fine, like he was going to grow out of it. (Cathy)My mother said we should have adopted an American child. (Doug) My parents were more loving toward him this last spring, I think because he had made a lot of progress since the last time we visited at Thanksgiving time. We put him in a mainstream school and put him back in day care, so he is a lot more verbal and has more social skills, so I think they are coming around."
(Cathy) " I don't have a close relationship with her. She sends him stuff, she asks about him and have never made a lot of effort to come here. She is a nice person, I love her, but I would never lean on her at all."

(David) "Yeah, I mean it was probably shock more than anything, I honestly don't remember because there was probably some more of mental shock going on just trying to comprehend that news. I mean I was probably more concerned about Cathy's reaction, but I mean I certainly wasn't jumping up and down for joy. I have two cousins who are both, one severely autistic and one more moderately, so I kind of have that reference point in the back of my mind as what to expect when he gets older, but I don't think about it that much."

"We are in our mid to late 30's and when we brought him home, what is his future? I mean for me I didn't think in hindsight you thing about it like oh my gosh are we going to have a great retirement and do our own thing that didn't cross my mind. Like is he going to, what happens when I die? What if we don't have more kids?
He's social, he's happy, he can't do a lot of things other kids his age can, but he gets along with people and he loves people. He's mentally retarded technically, so who can take advantage of him or hurt him and make him unhappy so that is my biggest fear."

Nancy (27), mother of a 7 year old son diagnosed with Significant Multiple Disabilities reports:

> I found out there was a problem when I was about 20 to 22 weeks. They didn't know what the implications would be and they didn't know if he would survive the rest of the pregnancy or even childbirth. I panicked at first, I was advised to terminate and the one thing that went through my mind was no. I've heard his heartbeat, this is my son. It was just, it's like you go into survival mode."
>
> I keep everything from all the diagnoses, test and procedures about his medical history on a flash drive and have printed copies. I keep a list of his disabilities with the implications that follow him wherever he goes. I have found myself telling doctors what a condition is and what it mean, that is kind of scary. Doctors have told me to lower my expectations. I celebrate the achievement's he has. The reality is that he is not normal; he will always need care and will never live a normal life.
>
> This is all too much and always I have the thought of what if I screw up and something I should have done and he is sick from it. You have your own expectations for them. You have your long term outlook.
>
> I learned to be his advocate because if I didn't nobody else would. My son is not broken he is just different. He has made me stronger. My whole goal is to make sure that he grows and thrives. You have to learn how to ask questions and get your answers and fight for your child. The key in all of this is that you know your child better than anyone.
>
> Really whenever they threw things out there about my son, I just researched everything. I didn't take much time to think about anything except what is this, and what is the best course of action. That is the way his whole life has been. It is impossible to focus on yourself for quite a few years. There is a lot that I had hoped to accomplish that I haven't. I get tired and drained emotionally.
>
> There have been times where I wonder where would I be if I hadn't had him but I don't stay there long. I believe my son saved me from myself. I have discovered a lot more of me and what I'm truly capable of. He has made me stronger. My resounding sorrow and fear for him is that someone will hurt him. It's always right there under the surface. I wouldn't trade a day of what I have lived with my son because it has been amazing and a privilege.

My parents have always been involved with my son and if not for them I'm not sure where I would be. They are my committee with my son.

I remarried in 2007. Having a second parent is very different because I made all the decisions before. I have someone to argue with, my husband. He is very involved and wants to understand and know about my son. He is very serious and looks at my son as his own. He is never embarrassed by him or to take him anywhere.

Cassie (39), mother of a seven and half year old daughter diagnosed with Angelman's syndrome.

The day they told us something was really really wrong, she was about 9 months. She had started missing a lot of milestones. I mean it was just so devastating. This is huge, it weighs heavy.

We never received a diagnosis in black and white, we had 8 different diagnosis of what they thought she had, and they were matter of fact without follow up. I used to fly by the seat of my pants; I used to be the fun in the relationship. Our environment is so controlled. If we hadn't had her we wouldn't be together. Marriage, this is hard on them. It's not all about me and that is good.

I'll be alright; I have this conversation with myself everyday or every night about 2 am when I can't go to sleep. It's not like when someone dies and you grieve. Our anger comes a little quicker, and our sadness comes a little quicker
You just do it, but really people don't know how you just do it, it's crazy. It makes you grow up, it makes you come undone. Keeps me in a good place.
"I went back to church. I got my daughter in a special needs ministry. I have become a full time parent. I started a support group; work with my school district and community. I just made my own friends, found my own friends and got my own people.

Well I never thought that I would be taking care of someone forever. She will still irritate me and make me happy. I still don't even know her. I look at her half the time and wonder what do you get what do you see, what do you understand?. I don't think I can buy a book with answers. My greatest fear is when the school bus doesn't show up anymore. I feel like the clock is ticking to the time when I will be alone with my daughter. She's never going away. God it's like Friday afternoon.

It's not like when someone dies and you grieve. It's not something that goes away, it's always there. Our anger comes a little quicker and our sadness comes a little quicker. Be careful what you ask for when you need a purpose. I don't see myself with a career, because this is what I do now.

My stepmom always asks about my plans for my daughter when she is 24. I can't talk about that yet, I don't know. My husband is not very close to his family at all.

We really had a hard time. So we almost split up and really didn't talk about her birth until 2 years after we were sitting in a lawyer's office thinking we had a case to go after the Dr.'s. This was the first time I ever knew how he felt about the whole thing. We still really don't talk about it. We, he and I handle things very very differently, so we just get in a weird place when we start talking about it so. He grew up with a brother who was adopted and was a lot like our daughter and um they put him in a home. He lives in a home in Fort Worth now. So I'm always kind of like, how do you want to think about her, ya know? I'm the only one here to protect her forever, ya know.

I don't even know where to start. I mean, you don't walk around and ask typical parents what they are going to do with kids when they are 16, or 18. I really don't know what she has that we can capitalize on. I mean her quality of life is jumping on the trampoline. I am it, we (my husband and I) don't travel together anymore-we have will written up. I try not to think too much about it—just something else to freak me out.

Denise (54), mother of an eighteen year old male diagnosed with Fragile X reports:

> We had to find out what it is cause he can't tell us. We were shocked and didn't understand at that point. Simple things that would not seem big, would be devastating as far as in the pit of stomach. You know you just feel sick, you just want to bawl. Yes it's over-whelming; it was overwhelming learning about the disorder. I felt small and overwhelmed, I felt totally inadequate.
>
> I just go through a tsunami of feelings and it was overwhelming.
> That's when we started to grieve for the child we didn't have and dealing with that and learning to cope with it.
>
> I mean after I got over the grief of the child I wasn't going to have and knew and came to grips with the fact that he was a gift, he was still a child, he was still my child, there was not planning in this, we didn't do this, this happened for a reason. I don't really like pity from friends, family or whatever from anybody. It is overwhelmingly special, deep and something beautiful
>
> I just needed to go back to me because I was so overwhelmed. I couldn't figure out where I wanted to go. When I'm overwhelmed I had to look to find what it is that will cause me to be filled up again. I go out to movies and I go out with friends and listen to their stories of their families. Sitting in the backyard and back porch saying prayers for other keeps me balanced.
> I began to understand what I got, meaning what my son had and what I got as a parent. I just go through this tsunami of feelings and it was overwhelming. It's going to be okay. I had to turn to me and decide what I wanted for my child.
>
> I mean after I got over the grief of the child I wasn't going to have and knew and came to grips with the fact that he was a gift, he was still a child, he was still my child, there was no planning in this, we didn't do this, this happened for a reason. It is probably the most beautiful experience I will probably even have in my life is what I have with him. I feel very lucky to have that. My job is to teach him to have an independent happy life.
>
> Well mom was a great teacher and dad had a PhD in psychology and he understood it I guess in generalities, but neither of them go the depth of what it was going to mean or could be proud of that, or of what they had. My husband's family lives in another state; they still don't really get it, what it means to have a child with special needs. I mean our extended families, they love him but they

don't really know how to communicate with him. So I guess since I never had it, they'll miss the joy that I see and feel.

My husband, I think like typical males, 60% of all husbands leave because they can't deal with that, said ya know I'm leaving at some point.
It is not only our job to help our kids but it is our job to help our spouse because their identity is tied to their family and their work. And if that is not running smoothly or to a point where they can understand and cope with it then everything falls apart. It's really our job to help them too-its overwhelming.

The majority of parent's keep their children until they are so old and can't care for them no more and then the separation takes place, which isn't fair for the child. And whatever it took for me to get over my selfishness and protectiveness needed to happen. I think it is much harder for my husband to not be caring and have to be vulnerable, but now that we've crossed over, the guardianship, the wills have all been made and the finances together. We will look for place for him to move where he would be able to become a productive part to his life, we have decided when he is 24. Who you leave them with legally is a huge and impossible thing, making the right decisions and having the sense of peace you have given your child the basics to go through anything. It's definitely going to be hard.

Ruth (40), mother of two adult males, (26, and 25) diagnosed with Fragile X, Autism and Tourettes Syndrome reports:

> People thought something was wrong with me cause I kept saying something was wrong with my boys. I felt trapped
>
> We went to countless numbers of doctors but all of them just said they were boys and I was overreacting. No one would listen. They gave me pamphlets to read, I read it, and I thought it was stupid, but the words didn't mean anything to me on paper.
>
> I wanted someone to tell me what life was going to be like in the future. I wanted someone to tell me what life was going to be like now, but I wanted to know, I wanted someone to tell me is my life going to suck, are we going to have a decent life, but no one could tell me that. It was cool when they were younger because it really didn't faze me, as they have grown older it is a whole new ball game.
>
> I have a lot to offer people, the kid's have a lot to offer people, but the bottom line is life goes on. Their hearts and souls are just so beautiful. A year or two years ago people knew I could go out and tell the whole work about my kids and do trainings and everything else. There was a sense of security then, a sense of balance and sense of village. I've lost that. Now I just feel like it is more enclosed.
>
> I don't listen to people as much as I used to. I'm pretty hard core in telling people where to go quick. Way more opinionated and I don't apologize for that.
>
> There comes a point when you get tired of raising kids and it's not that I'm sick of raising my kids, it's just for the rest of my life I will be doing this. I wouldn't change it cause even if there was a magic pill I wouldn't give it to them cause I still think I am more blessed than most people because I don't know hardly anybody who can get hugs, kisses and prayer and know that they are so beautiful.
>
> So as they were little it was sad, I had to deal with a bunch of people in the family and their dad's family that thought they had cooties or something. They kept saying you just need to treat them like they are normal and they will snap out of it. And I'd think, oh yeah let's find that magic pill! But dealing a lot with ignorant family, they didn't care about nothing else except being comfortable. It made them uncomfortable so they wanted me to change everything to make them comfortable.

I have wills, and insurance policies I pay on every month. My oldest son will always be with someone. My youngest son has the luxury of being able to function in that type of setting (group home). My oldest can't. He is so fragile; he could never go into a home or anything like that. They don't care. They would treat him as a category and they would put him in there because he can't clean his heney or whatever. And he would lay there in a bed of poop. If he throws up, he gets the hiccups. They aren't going to take care of that. He's just a number and may even die in a bed and a lot has to do with controlling the environment. Me leaving before them I think is more of a reality now then it was when I was younger.

Maria (51), mother of a 29 year old male diagnosed with Mental Retardation and Autism.

When I found out his diagnosis I was so young. I was 27 years old and he is my first child so I did not know what in the world they were meaning about Autism. I was confused. I did not know what questions to ask. I did not know where to go for help and um I was devastated on one side on the other side I was so eager to get all the information I could to help him.

I would go to the library and get the books I needed, bring them home and read and read I kind of trained myself. I had to quit college. I think that was a priority with me, more than grieving. I don't think that I went through the grieving process the normal way. I think I just jumped from beginning to end because I did not have time to lose.

My son taught me how to be patient. I have a lot of potential. I will be the best mom that my son can have and maybe that is what is important.

Maybe it is not important that I make $100,000 a year but that I understand that my son is here for a reason and given to me to for a reason to be a better person and to help others. I'm still going to school for myself and for my son and daughter, because I need to do something for myself, and for my son and daughter to know they can if they choose.

To this day the hardest thing for me when I had my son with a disability and my other two children was having to switch my brain from dealing a certain way with my son and to switch my brain to deal another way with my other two. I always felt I was short changing the other two. I knew I could do anything I wanted to do so I did have a sense of loss, and I was realistic at the same time. This was my mission as to what to expect and what not to expect. Nothing catches me by surprise.

It's not my way, it was not my plan it was God's plan. It wasn't my purpose in life it was God's. This is more important than a career because you are able to see how in some way you were able to impact someone's life.

I never had a problem with extended family. I guess they were okay because they weren't in close contact to live it every day. I think my mom felt bad because I had to quit college.

My husband was not admitting that something was wrong with his first child. He said that I was the one who was crazy and that I was the one who was psycho analyzing everybody. Once our son was diagnosed my husband pretty much went into a shell, didn't want to deal with the diagnosis. I left my husband twice. It was always me pushing him out or me leaving. When he came back I told him, you either stay with me for the long run and know that your son has a disability and its permanent. You're not going to sleep and wake up and he's going to be fine. He stayed. He is not perfect. He love our son, he bathes him, takes care of him, he loves and he does whatever he need to do. He was struggle and I pushed him to make a decision.

Lisa and I have talked about it a couple of times. I've told Lisa if she passes away before I do and her husband and if it is okay with them I will take care of their son. For my son, I have a special needs trust and an attorney who will take care of that for me. As far as where he is going to, I don't know yet. Because I don't want to put that on my son and daughter.

Lisa (70), mother of a 30 year old male diagnosed with Autism and Seizure Disorder reports:

It was a challenge for me, I keep going on. I'm upset not because something wrong, I had to fight to find a solution. They say he is normal but deep down inside I could not understand it but everyone says he is normal, they keep saying it.

I did not know because we did not ever get the diagnosis until he was 15 years old. I treat him like a normal child, he travelled with me. I just thought if you have to talk or say something to him 100 times you do it a hundred times. I had one doctor wake me up, he said go home and find therapy, OT, PT and Speech and work with him.

This is a lifetime, you have to be strong and care for him, we have to have an attitude to believe and to try, it is so important.

My husband tells me we are so lucky to have our son because the child is like God because he has taught us so much. I know I have to be strong.

But my son have brain damage because he right now he almost 30 years old and he is like a two year old. When he was small we didn't know all these things. I never think my son Scott have a problem for so many years. I know he wasn't normal but I never think he has handicap.

I feel like God teach me many things I don't know. Since I have my son, I learn more and I'm not as scared as I used to be I have changed how I think and am with others. My son taught me a lot of things like patience. I know I have to be strong. I believe God has used me to help other Asian families by being strong and encouraging them to treat their child as a gift no matter their limitations. My son taught us many things.

My family support 100% and spoil him rotten. You know they feel that he's the black sheep for all the family; he has the support from everyone in the family. You have that life because he suffered for you. So everybody have to like owe him something, they spoil him. They were serving him, my son was Mr. God. Everywhere he goes he have to be first. They say I am a mean mommy because I say he delayed, he has therapy, you have to push him but they cater to him you know. They say, Oh he cannot not do it. I say that is why we have therapy and pay for therapy. But you know they say you have to hold the spoon, oh he cannot.

We used to. In the last 10 years we have changed our minds. We used to think family would care for our son, now we have changed our minds. It is easy to forget our son because he can lie down and sleep but not sleep. We want to set up a group home to hire and train staff to care for the children. We think we would like to have 3 other men in the home with our son that will live and have friendship and people to care them as they should.

APPENDIX I
DISABILITY DIAGNOSES

Angelman Syndrome (http://www.mayoclinic.com/AngelmanSyndrome.htm).

Angelman syndrome is a genetic disorder that causes developmental disabilities and neurological problems, such as difficulty speaking, balancing and walking and, in some cases, seizures. Frequent smiles and outbursts of laughter are common for people with Angelman syndrome, and many have happy, excitable personalities.

If your child has Angelman syndrome, you may not see any signs at birth. Angelman syndrome usually isn't detected until parents begin to notice developmental delays when a baby is about 6 to 12 months old. Seizures often begin when a child is between 2 and 3 years old.

Treatment for Angelman syndrome focuses on managing the child's medical and developmental problems.

Symptoms

Characteristic Angelman syndrome signs and symptoms include:

- Developmental delays, such as lack of crawling or babbling at 6 to 12 months, and mental retardation
- Lack of or minimal speech
- Inability to walk, move or balance well (ataxia)

- Trembling movement of arms and legs
- Frequent smiling and laughter
- Happy, excitable personality

People who have Angelman syndrome may also have other signs and symptoms, including:

- Seizures, usually beginning between 2 and 3 years of age
- Stiff or jerky movements
- Small head size, with flatness in the back of the head (microbrachycephaly)
- Crossing of the eyes (strabismus)
- Tongue thrusting
- Walking with arms up in the air
- A lower jaw that juts out
- Light pigmentation in hair, skin and eyes (hypopigmentation)

Autism (http://www.mayoclinic.com/Autism.)

Autism is one of a group of serious developmental problems called autism spectrum disorders (ASD) that appear in early childhood — usually before age 3. Though symptoms and severity vary, all autism disorders affect a child's ability to communicate and interact with others.

The number of children diagnosed with autism appears to be rising. It's not clear whether this is due to better detection and reporting of autism, a real increase in the number of cases, or both.

While there is no cure for autism, intensive, early treatment can make a big difference in the lives of many children with the disorder.

Symptoms

Children with autism generally have problems in three crucial areas of development — social interaction, language and behavior. But because autism symptoms vary greatly, two children with the same diagnosis may act quite differently and have strikingly different skills. In most cases, though, severe autism is marked by a complete inability to communicate or interact with other people.

Some children show signs of autism in early infancy. Other children may develop normally for the first few months or years of life but then suddenly become withdrawn, become aggressive or lose language skills they've already acquired. Though each child with autism is likely to have a unique pattern of behavior, these are some common autism symptoms:

Social Skills

- Fails to respond to his or her name
- Has poor eye contact

- Appears not to hear you at times
- Resists cuddling and holding
- Appears unaware of others' feelings
- Seems to prefer playing alone — retreats into his or her "own world"

Language

- Starts talking later than age 2, and has other developmental delays by 30 months
- Loses previously acquired ability to say words or sentences
- Doesn't make eye contact when making requests
- Speaks with an abnormal tone or rhythm — may use a singsong voice or robot-like speech
- Can't start a conversation or keep one going
- May repeat words or phrases verbatim, but doesn't understand how to use them

Behavior

- Performs repetitive movements, such as rocking, spinning or hand-flapping
- Develops specific routines or rituals
- Becomes disturbed at the slightest change in routines or rituals
- Moves constantly
- May be fascinated by parts of an object, such as the spinning wheels of a toy car
- May be unusually sensitive to light, sound and touch and yet oblivious to pain

Young children with autism also have a hard time sharing experiences with others. When read to, for example, they're unlikely to point at pictures in the book. This early-developing social skill is crucial to later language and social development.

As they mature, some children with autism become more engaged with others and show less marked disturbances in behavior. Some, usually those with the least severe problems, eventually may lead normal or near-normal lives. Others, however, continue to have difficulty with language or social skills, and the adolescent years can mean a worsening of behavioral problems.

Most children with autism are slow to gain new knowledge or skills, and some have signs of lower than normal intelligence. Other children with autism have normal to high intelligence. These children learn quickly yet have trouble communicating, applying what they know in everyday life and adjusting in social situations. A small number of children with autism are "autistic savants" and have exceptional skills in a specific area, such as art, math or music.

Fragile X Syndrome (www.nlm.nih.gov.FragileXSyndrome.htm.)

Fragile X syndrome is a genetic condition involving changes in part of the X chromosome. It is the most common form of inherited mental retardation in males and a significant cause of mental retardation in females.

Causes

Fragile X syndrome is caused by a change in the FMR1 gene. A small section of the gene code (three letters only -- CGG) is repeated on a fragile area of the X chromosome. The more repeats, the more likely there is to be a problem.

Normally, the FMR1 gene makes a protein needed for your brain to grow properly. A defect in this gene makes your body produce too little of the protein, or none at all.

Boys and girls can both be affected, but because boys have only one X chromosome, a single fragile X is likely to affect them more severely. You can have Fragile X syndrome even if your parents do not have it.

Fragile X syndrome can be a cause of autism or related disorders, although not all children with fragile X syndrome have these conditions.

Symptoms

Behavior problems associated with fragile X syndrome include:

- Delay in crawling, walking, or twisting
- Hand clapping or hand biting
- Hyperactive or impulsive behavior
- Mental retardation

- Speech and language delay
- Tendency to avoid eye contact

Physical signs may include:

- Flat feet
- Flexible joins and low muscle tone
- Large body size
- Large forehead or ears with a prominent jaw
- Long face
- Soft skin

Some of these problems are present at birth, while others may not develop until after puberty.

Family members who have fewer repeats in the FMR1 gene may not have mental retardation, but may have other problems. Women with less severe changes may have premature menopause or difficulty becoming pregnant. Both men and women may have problems with tremors and poor coordination.

Mental Retardation (http://www.nlm.nih.gov.MentalRetardation.htm.)

Mental retardation is a condition diagnosed before age 18 that includes below-average general intellectual function, and a lack of the skills necessary for daily living.

Causes

Mental retardation affects about 1 - 3% of the population. There are many causes of mental retardation, but doctors find a specific reason in only 25% of cases.

A family may suspect mental retardation if the child's motor skills, language skills, and self-help skills do not seem to be developing, or are developing at a far slower rate than the child's peers. Failure to adapt (adjust to new situations) normally and grow intellectually may become apparent early in a child's life. In the case of mild retardation, these failures may not become recognizable until school age or later.

The degree of impairment from mental retardation varies widely, from profoundly impaired to mild or borderline retardation. Less emphasis is now placed on the degree of retardation and more on the amount of intervention and care needed for daily life.

- Continued infant-like behavior
- Decreased learning ability
- Failure to meet the markers of intellectual development
- Inability to meet educational demands at school
- Lack of curiosity

Note: Changes to normal behaviors depend on the severity of the condition. Mild retardation may be associated with a lack of curiosity and quiet behavior. Severe mental retardation is associated with infant-like behavior throughout life.

Epilepsy (http://www.nlm.nih.gov.SeizureDisorder.htm.)

Epilepsy is a brain disorder involving repeated, spontaneous seizures of any type. Seizures ("fits," convulsions) are episodes of disturbed brain function that cause changes in attention or behavior. They are caused by abnormally excited electrical signals in the brain.

Causes

Seizures ("fits," convulsions) are episodes of disturbed brain function that cause changes in attention or behavior. They are caused by abnormally excited electrical signals in the brain.

Sometimes a seizure is related to a temporary condition, such as exposure to drugs, withdrawal from certain drugs, a high fever, or abnormal levels of sodium or glucose in the blood. If the seizure or seizures do not happen again once the underlying problem is corrected, the person does NOT have epilepsy.

In other cases, permanent injury to or changes in brain tissue cause the brain to be abnormally excitable. In these cases, the seizures happen without an immediate cause. This is epilepsy. Epilepsy can affect people of any age.

Epilepsy may be idiopathic, which means the cause cannot be identified. These seizures usually begin between ages 5 and 20, but they can happen at any age. People

with this condition have no other neurological problems, but sometimes have a family history of seizures or epilepsy.

Symptoms

The severity of symptoms can vary greatly, from simple staring spells to loss of consciousness and violent convulsions. For most people with epilepsy, each seizure is similar to previous ones. The type of seizure a person has depends on a variety of things, such as the part of the brain affected and the underlying cause of the seizure.

An aura consisting of a strange sensation (such as tingling, smelling an odor that isn't actually there, or emotional changes) occurs in some people prior to each seizure.

Tourette Syndrome (http://www.nlm.nih.gov.TouretteSyndrome.htm.)

Tourette syndrome (TS) is a neurological disorder characterized by repetitive, stereotyped, involuntary movements and vocalizations called tics. The disorder is named for Dr. Georges Gilles de la Tourette, the pioneering French neurologist who in 1885 first described the condition in an 86-year-old French noblewoman.

The early symptoms of TS are almost always noticed first in childhood, with the average onset between the ages of 7 and 10 years. TS occurs in people from all ethnic groups; males are affected about three to four times more often than females. It is estimated that 200,000 Americans have the most severe form of TS, and as many as one in 100 exhibit milder and less complex symptoms such as chronic motor or vocal tics or

transient tics of childhood. Although TS can be a chronic condition with symptoms lasting a lifetime, most people with the condition experience their worst symptoms in their early teens, with improvement occurring in the late teens and continuing into adulthood.

What are the Symptoms?

Tics are classified as either simple or complex. Simple motor tics are sudden, brief, repetitive movements that involve a limited number of muscle groups. Some of the more common simple tics include eye blinking and other vision irregularities, facial grimacing, shoulder shrugging, and head or shoulder jerking. Simple vocalizations might include repetitive throat-clearing, sniffing, or grunting sounds. Complex tics are distinct, coordinated patterns of movements involving several muscle groups. Complex motor tics might include facial grimacing combined with a head twist and a shoulder shrug. Other complex motor tics may actually appear purposeful, including sniffing or touching objects, hopping, jumping, bending, or twisting. Simple vocal tics may include throat-clearing, sniffing/snorting, grunting, or barking. More complex vocal tics include words or phrases. Perhaps the most dramatic and disabling tics include motor movements that result in self-harm such as punching oneself in the face or vocal tics including coprolalia (uttering swear words) or echolalia (repeating the words or phrases of others). Some tics are preceded by an urge or sensation in the affected muscle group, commonly called a premonitory urge. Some with TS will describe a need to complete a tic in a certain way or a certain number of times in order to relieve the urge or decrease the sensation.

Tics are often worse with excitement or anxiety and better during calm, focused activities. Certain physical experiences can trigger or worsen tics, for example tight collars may trigger neck tics, or hearing another person sniff or throat-clear may trigger similar sounds. Tics do not go away during sleep but are often significantly diminished.

APPENDIX J
TABLE 1 PARENT PARTICIPANTS

Table 1

Parent Participants

Parents/Age	Child/Age	Diagnosis
Cathy (34) **David (38)**	Male (3 1/2)	Fragile X
Ruth (40)	Male (28, 25)	Tourettes, Autism, Fragile X
Cassie (39)	Female (7)	Angelman's
Denise (54)	Male (18)	Fragile X
Nancy (27)	Male (7)	Multiple Disabilities
Maria (51)	Male (29)	Mental Retardation and Autism
Lisa (70)	Male (30)	Autism and Seizure Disorder